DOCUMENT RESUME

ED 394 699 PS 024 144

AUTHOR McCann, Thurma; And Others
TITLE The Healthy Start Initiative: A Community-Driven Approach to Infant Mortality Reduction. Volume III: Sustainability.
INSTITUTION National Center for Education in Maternal and Child Health, Arlington, VA.
SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Washington, DC. Maternal and Child Health Bureau.
REPORT NO ISBN-1-57285-024-8
PUB DATE 95
CONTRACT MCU-117007
NOTE 122p.; For volume 1, see ED 375 953; for volume 2, see ED 381 261.
AVAILABLE FROM National Maternal and Child Health Clearinghouse, 2070 Chain Bridge Road, Suite 450, Vienna, VA 22182-2536 (single copy is free of charge).
PUB TYPE Books (010) -- Reports - Descriptive (141)

EDRS PRICE MF01/PC05 Plus Postage.
DESCRIPTORS Agency Cooperation; Child Development; Community Development; Coordination; Economic Development; Government Role; *Infant Mortality; Prevention; *Program Evaluation; *Public Health; Resources; *Social Change; Substance Abuse; Violence
IDENTIFIERS *Healthy Start Program; Maternal and Child Health Services; Medicaid; *Sustainability

ABSTRACT

The Healthy Start Initiative is a national five-year demonstration program that uses a broad range of community-driven, system development approaches to reduce infant mortality and improve the health and well-being of women, infants, children, and families. This volume, third in the series, deals with the topic of sustainability, which refers to efforts by the projects to continue the successful strategies that only recently have progressed from early implementation toward a model of success. It is claimed that the best products are those derived after careful planning and deliberation. The efforts of the communities involved in the Healthy Start Initiative provides meaningful examples of interventions that can be replicated in other environments. This report has three chapters. The first chapter, entitled "Healthy Start's Environment: Capitalizing on Change," discusses the changes in Medicaid and managed care, federal resources, violence prevention, child development, maternal and child health, and community development. The second chapter, entitled "Evaluating Impact: Telling the Healthy Start Story," discusses local evaluation of the Healthy Start Initiative program as well as public information and public education campaigns. The third chapter, entitled "Linking with Stakeholders: Building Bridges to Resources," discusses the importance of leadership, momentum, involvement, and diversity of community. It also provides information on private resources. An appendix which provides a list of related organizations is included. (MOK)

PS

# THE HEALTHY START INITIATIVE

## A COMMUNITY-DRIVEN APPROACH TO INFANT MORTALITY REDUCTION

ED 394 699

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

X This document has been reproduced as received from the person or organization originating it.

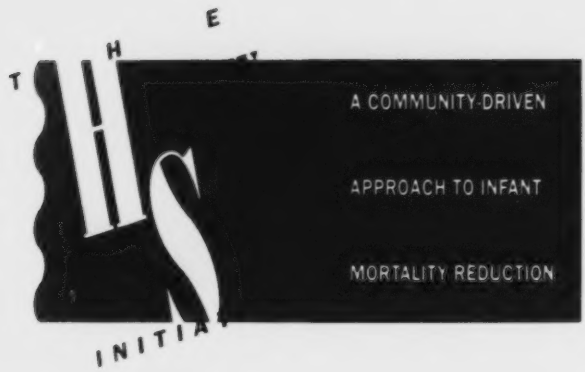
☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

PS 024144

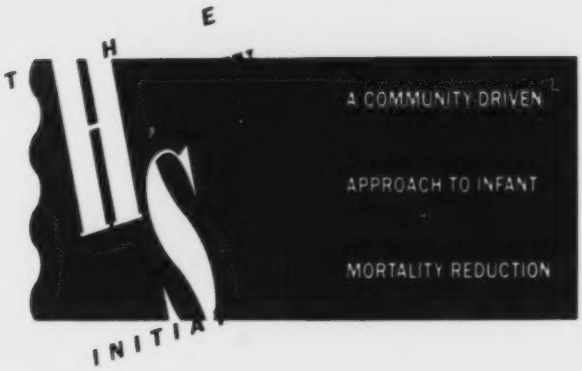


BEST COPY AVAILABLE




**Volume III**

# Sustainability




## Volume III

# Sustainability

Thurma McCann, M.D., M.P.H., Director
Bernice W. Young, Deputy Director
Donna Hutten, R.N., M.S., Branch Chief

Division of Healthy Start
Maternal and Child Health Bureau
Health Resources and Services Administration
Public Health Service
U.S. Department of Health and Human Services

**Editors**

Debra Lightsey, Meri McCoy-Thompson,
Stephanie Cox, Angelica Dirtadian

**Published by**

National Center for Education in Maternal and Child Health
Arlington, Virginia

**Cite as**
McCann T, Young, BW, Hutten D. 1995. *The Healthy Start Initiative: A Community-Driven Approach to Infant Mortality Reduction—Vol. III. Sustainability.* Arlington, VA: National Center for Education in Maternal and Child Health.

*Sustainability*, the third book in the *Healthy Start Initiative: A Community-Driven Approach to Infant Mortality Reduction* series, is not copyrighted. Readers are free to duplicate and use all or part of the information contained in this publication. In accordance with accepted publishing standards, the National Center for Education in Maternal and Child Health (NCEMCH) requests acknowledgment, in print, of any information reproduced in another publication.

The Healthy Start Initiative is a demonstration program funded under Section 301 of the Public Health Service Act to identify a broad range of community-driven strategies and interventions which could successfully and significantly reduce infant mortality. This Initiative is currently supporting 22 urban and rural communities to implement such strategies and interventions.

The mission of the National Center for Education in Maternal and Child Health (NCEMCH) is to promote and improve the health, education, and well-being of children and families by leading a national effort to collect, develop, and disseminate information and educational materials on maternal and child health; and by collaborating with public agencies, voluntary and professional organizations, research and training programs, policy centers, and others to advance knowledge in programs, service delivery, and policy development. Established in 1982 at Georgetown University, NCEMCH is part of the Graduate Public Policy Program. NCEMCH is funded primarily by the U.S. Department of Health and Human Services through its Maternal and Child Health Bureau.

Library of Congress Catalog Card Number 95-72697
ISBN 1-57285-024-8

*Published by:*
National Center for Education in Maternal and Child Health
2000 15th Street North, Suite 701
Arlington, VA 22201-2617
(703) 524-7802
(703) 524-9335 fax
Internet: ncemch01@gumedlib.dml.georgetown.edu

*Single copies of this publication are available at no cost from:*
National Maternal and Child Health Clearinghouse
2070 Chain Bridge Road, Suite 450
Vienna, VA 22182-2536
(703) 821-8955
(703) 821-2098 fax

*This publication has been produced by the National Center for Education in Maternal and Child Health under its cooperative agreement (MCU-117007) with the Maternal and Child Health Bureau, Health Resources and Services Administration, Public Health Service, U.S. Department of Health and Human Services.*

# Contents

Acknowledgments ..... vi

Foreword ..... vii

Introduction ..... ix

**Chapters**

1. Healthy Start's Environment: Capitalizing on Change ..... 5
2. Evaluating Impact: Telling the Healthy Start Story ..... 35
3. Linking with Stakeholders: Building Bridges to Resources ..... 57

**Conclusion:** Sustaining Healthy Start Projects ..... 101

Appendix ..... 103

# Acknowledgments

We wish to thank all those who contributed to this volume. Most importantly, we wish to thank those individuals whose voices are the basis of this book—those who shared their experiences at the 1994 Annual Healthy Start Grantee Meeting. It is their stories that are presented in the pages that follow. These stories came from speakers, whose names are cited below, but also from other meeting attendees. In all sessions, Healthy Start staff and consumers enthusiastically offered their knowledge in the true spirit of collaboration. Special thanks to Valerie Gwinner for her guidance in the final stages of developing this book. Our special thanks also go to Lillie Fox, Lillian Armstrong, Jimmie Brown, and Tameka Coleman—their stories are at the heart of Healthy Start.

**In Chapter 1**

Peter van Dyck, Susan Tucker, Joan Savoy, David Heppel, Frank Bonati, Chester Pogostin, Mary Knipmeyer, Moniquin Huggins, Roy Priest, Caroline Lewis

**In Chapter 2**

Zoe Clayson, Dorothy Jones Jessup, Nathalie Vanderpool Bartle, Patricia O'Campo

**In Chapter 3**

Joseph Reid, Mildred Thompson, Gloria Cox-Crowell, Madie Robinson, Michelle Drayton-Martin, Deborah Jack, Lillie Fox, Roy Priest, Nolan Lewis, Deborah Francis, Paul Vander Velde, Robert Beggan, Patricia Pasqual, William Randolph, Molly Guard, Patty & Lynne Gartenhaus, Michelle Lecks, Roland Loudenberg

* *Contact information for speakers can be found in the Appendix.*

# Foreword

The Healthy Start Initiative is a national five-year demonstration program that identifies a broad range of community-driven, systems development approaches to reduce infant mortality and improve the health and well-being of women, infants, children, and families.

In 1991, the U.S. Department of Health and Human Services funded entities in 15 rural and urban communities that had infant mortality rates 1.5 to 2.5 times the national average. An additional seven sites were funded in 1994 as special projects with the goal of significantly reducing infant mortality. These 22 projects are implementing innovative approaches to coordinated, comprehensive, culturally competent models of health and other facilitative services, which can reduce a community's infant mortality.

At the 1994 Healthy Start grantee meeting, representatives from Healthy Start sites and other experts shared strategies that are used as the basis for this volume, *Sustainability*. Because of widespread interest in learning about Healthy Start, what the projects have done, and how they have established coalitions within the community, this publication is part of a multivolume series, *The Healthy Start Initiative: A Community-Driven Approach to Infant Mortality Reduction*. The series of publications provides a mechanism by which current and critical information about the projects' activities can be shared and widely disseminated. Other volumes in the series include:

- *Volume I: Consortia Development (Spring 1994)*
- *Volume II: Early Implementation—Lessons Learned (Fall 1994)*
- *Volume IV: Community Outreach Strategies (forthcoming)*
- *Volume V: Healthy Start Innovations (forthcoming)*

The ideas and strategies presented here have formed the framework for discussion between local consortia and state Title V directors as well as between project staff and public and private providers and agencies that share the commitment to decrease infant mortality within the United States.

Sustainability is a term used to describe efforts by the projects to continue the successful strategies that only recently have progressed from early

implementation toward a model of success. It is well known that the best products are those derived after careful planning and deliberation. The efforts of the communities involved in the Healthy Start Initiative provide meaningful examples of interventions that can be replicated in other environments. It is important to learn from them, to disseminate this useful information, and to pursue alternative resources in order to win the battle against infant death.

*Thurma McCann, M.D., M.P.H.*
*Director*
*Division of Healthy Start*
*Maternal and Child Health Bureau*
*Health Resources and Services Administration*

# INTRODUCTION

## The Path to Permanence: Sustaining Community-Based Initiatives

In 1991, the Healthy Start Initiative was charged with reducing infant mortality in 15 of the nation's most distressed communities.* This task required reaching beyond the well-being of newborns and encompassing mothers, fathers, families—indeed, whole communities. Taking on the responsibility to innovate, the Healthy Start sites have kept their promise in ways unimaginable four years ago. Focusing the power of collaboration on the problem of infant mortality, Healthy Start has brought together community strengths, transforming needy communities into Healthy Start communities. Today, the Healthy Start spirit is so deeply rooted in these communities that one can hardly imagine them without Healthy Start.

Today, the challenge is to keep these communities Healthy Start Communities—communities that are maintaining significantly lower infant mortality. These Healthy Start sites were funded as five-year demonstration projects; in order to last, they have to continue to innovate, this time in the area of sustainability. Staying power requires new abilities:

- The ability to capitalize on a changing environment
- The ability to tell the Healthy Start stories
- The ability to build bridges to resources, both public and private

Sustaining their own community-based initiatives and their own good efforts is quite a challenge for the Healthy Start sites. As demonstration projects, however, the Healthy Start sites also have a larger responsibility. To fulfill both their obligations as a demonstration project and their obligations to their communities, the sites must teach their lessons to others. Healthy Start successes can be replicated by other community-based initiatives, and the Healthy Start philosophy can be incorporated into communities across the

* In 1994, an additional seven sites were funded as Special Projects with the goal of significantly reducing infant mortality.

country. The power of collaboration can be focused on community problems of all kinds. The metamorphosis that Healthy Start has achieved is possible in other communities working to promote their own well-being.

In keeping with the spirit of spreading the Healthy Start philosophy, this book is intended for three audiences:

- Healthy Start sites and those involved with the Healthy Start Initiative
- Community-based initiatives that are faced with the challenge of sustainability or that seek to learn the lessons of Healthy Start, perhaps replicating its philosophy and methods
- Providers, agencies and community-based organizations that wish to get a preview of the experience gained from the Healthy Start Initiative

## Healthy Start's Environment: Capitalizing on Change

Healthy Start sites, like all community programs, need to be grounded in their environment while creatively recognizing opportunity in change. Assessing the environment is a crucial first step in planning for the future. Healthy Start sites need to continually scan their environments for paths to a

well-funded future, a future where the community continues to become stronger, while adapting to fit into new systems and new needs.

Healthy Start's environment, like other community-based projects, is multilayered and complex. It includes the local community: residents, agencies, government, economy, and many other factors specific to each site. The state environment also presents opportunities and challenges, as states continue to design and implement health care reform and other major shifts in social policy. Changes at the federal level are most removed from the day-to-day programs, but nonetheless crucial to mapping out the future. Changes at the federal and state level often ripple through Healthy Start's entire environment, creating new paths and closing off others.

Healthy Start must seek out these new paths and must recognize those that have become dead ends. Community-based programs need vision to find their place in emerging systems, while holding onto their role in existing systems. This book presents information on trends in state Medicaid programs, as well as many federal programs concerned with Healthy Start's goal and constituents. While not always providing a direct line to funding, these resources are important allies. They have different perspectives that will help Healthy Start accurately assess environments for new opportunities; in many cases, these initiatives directly touch the lives of Healthy Start consumers, now and in decades to come.

## Evaluating Impact: Telling the Healthy Start Story

The Healthy Start Initiative's national evaluation examines its outcomes, noting the changes in community infant mortality rates attributable to Healthy Start services. The national evaluation effort is also studying the processes by which programs have had an effect on this outcome, studying components such as community involvement, public information, outreach and case management, facilitative services, and service integration. The national evaluation tells the story of the national Healthy Start Initiative.

What gets lost in this aggregation are the stories of each Healthy Start site, the unique path each project walked with the community. In meeting the challenge to innovate and collaborate, each site has developed into a locally meaningful initiative. Each site has turned idealistic plans for community leadership into reality through consortia and collaboration. As a result, each of the 22 sites has unique structures and processes, and each has taken a

different journey from the ideal to the practical. It is this story that must be told for individual projects to be valued within their communities.

Local evaluations tell the story in terms of community impact—holistic results. This means going beyond the measure of reduced infant mortality to tell stories of family, institutional, and community outcomes. Healthy Start and similar initiatives rest on principles that guide not only what the projects do, but *how* they do it. Self-evaluation allows the community to reflect on its own efforts and impact. Highlighting impact means highlighting the process and all the strength uncovered by entering into partnership with the community.

Healthy Start stories must be credible: they must be based on sound evaluations, relying on qualitative as well as quantitative information. Because of the Initiative's complexity and uniqueness, evaluation can be difficult. This book presents methods and lessons learned in evaluating some common Healthy Start components: economic development/community empowerment, support services, consortia and governance, public information and education, and preventive services for adolescents. These components are priorities not only for Healthy Start, but for many community-based initiatives.

Knowing the Healthy Start story, or any story, is not enough. This Initiative and others like it must tell their stories and teach their lessons. Once Healthy Start sites have scanned their environments and can tell their story, they are ready to link with stakeholders—public, private, and community.

## Linking with Stakeholders: Building Bridges to Resources

The end of the federal Healthy Start Initiative will not be the end of the Healthy Start path. In order to sustain Healthy Start's work, sites need to build bridges to resources, creating a path to permanence. Bridges to resources must have partnerships at their foundation and must be continually built, maintained, and rebuilt.

Healthy Start communities include many stakeholders, public and private. Because Healthy Start has welcomed partners from all sectors since the beginning, this Initiative includes more diverse stakeholders than most. In fact, Healthy Start sites have worked diligently to turn community members into stakeholders, and stakeholders into partners. These partners include government agencies, hospitals, universities, Medicaid and other insurers, private foundations, health care providers, local businesses, schools,

CLEVELAND HEALTHY START

churches, and many others. Most of all, the community itself has a deep investment in Healthy Start and its goals.

Healthy Start sites need to bring stakeholders along with them on their paths, just as they have always done. Building on reliable evaluations, Healthy Start sites need to tell new partners the stories they care about most, focusing on Healthy Start's impact on their concerns. Different stakeholders will have different issues, and projects must customize their message to make stakeholders partners.

Strengthening consortia and community involvement is crucial to building new bridges. The community must feel Healthy Start successes as *its own* successes. Continued community ownership and leadership ensures that Healthy Start remains true to its values, and that the community continues to be one with Healthy Start.

Healthy Start sites need to walk with others on *their* paths, joining forces to reach mutual goals. Working together means helping each other, and community-based initiatives need to give to all of their partners in order to get the support they need to sustain the work. This book presents information and strategies for Healthy Start sites to build bridges with the community, with the private sector, and with each other.

Healthy Start's story should be told far and wide. If these bridges with communities, with stakeholders, and with each other are built, Healthy Start will be known as a crucial part of America's investment in the future. New stakeholders will emerge who never knew what Healthy Start did for them and their goals. Now is a time to gather all who benefit (or could benefit) from Healthy Start, and walk together toward permanence.

The first component of Healthy Start's purpose is to achieve successful, significant reduction in infant mortality, accomplished with the community. The second component is to teach Healthy Start's lessons. This book is part of the process of teaching Healthy Start's lessons to communities and programs that believe in community problem solving. This book holds lessons for other initiatives facing uncertain funding, as well as for budding programs invested in building on what has gone before. When the Healthy Start philosophy becomes the standard for community-based initiatives, Healthy Start will have truly fulfilled its purpose.

## CONSUMER VOICES

*Lillie Fox, Pee Dee Healthy Start*

Ms. Fox is the mother of four sons, ages 25, 19, 18, and 13. She became a single mother at the age of 17, and earned her high school diploma. Ms. Fox is the creator and director of Agape Placement, Inc., a counseling center and group home for unwed mothers in Darlington County, South Carolina. Ms. Fox represents local Healthy Start consumers on a number of committees with the consortium, and serves as the chairperson for the consumer coalition. She also volunteers with several organizations. These are her words.

"I'm here because I represent the consumers from Darlington County. The consumers and I had a meeting as soon as I found out what the theme was for this panel. From that meeting, I bring you their answers, suggestions, and requests. If I sound nervous, it's because I am.

"First, I would like to say that I got involved with Healthy Start because I was a teen mom at the age of 17. All of my children were low birthweight babies. They were healthy children. I didn't do everything right. Three of them were high-risk babies and I would love to have had a Healthy Start group such as the one I am working with now.

"Our staff in the Pee Dee is the most wonderful staff there is. Whenever there is a problem with a consumer, I call on 'Momma Madie,' because if she doesn't have the answer, there is not one time when she'll say 'I will call you back' when she doesn't. If she says she will call you back, she will. If she doesn't know the answer, she will find you the answer.

"I got involved with Healthy Start when the coordinator gave me a call, because I am a curiosity-seeker. I started going to meetings and at first I wouldn't say anything. I would approach the director afterward and tell her what my points-of-view were. Then I got invited to Washington and got a big mouth after that!

"We see the role between consumers and the community like the role of the umbilical cord between mother and child. The consumer

coalition serves not only as communicator from the grantee to the consumer population, but vice versa. Who knows the stress of a person with sick children better than someone who has actually walked in those shoes? Often, I intervene with people around issues such as how they will get to the doctor, how they will pay, whether they will be seen at all because the last bill hasn't been paid, whether the nurse or receptionist will announce to the whole waiting room that they are being turned away, etc. Through Healthy Start, we have had a lot of those barriers torn down. A lot of them still exist, but a lot have been torn down. In order for us to know how well we are doing, we have to know how bad things were in the beginning.

"The challenge is to stretch an innovative and creative pathway to overcome traditional forces of bureaucracy and red tape. Consumers meet and providers come to us and ask us for our recommendations. We pour our hearts out, sometimes making fools of ourselves telling them the things we think need to be done. Then we monitor them, and the things that they promised are not being done. The first thing they tell us is that they have to call Washington. Well, when we were there telling them what we thought needed to be done, and they were asking us questions, nobody said that they had to call Washington. Practice what you preach. If you promise me an apple, when the time comes for me to eat that apple, don't hand me an orange. Are the right questions being asked? Does every grassroots idea need a rubber stamp? We realize that people just don't give you money and not come around later to see what you've done with it. That happens in your own household. If you had twenty dollars, and it's gone, you want to know what happened to it. So, it is logical for Washington to want to know what happens to the money. That's okay, but sometimes I think that the providers need to communicate the problems to Washington before they ask the consumers for their input.

"About sustainability, those of us in the Pee Dee need to come together to decide what is creative and innovative. What the consumers view the meaning to be is completely different from what the providers view the meaning to be. I'll tell you, and so can Dr. McCann and her staff, that I don't mind writing letters. I don't mind calling and I don't mind contributing all that I can contribute, but there has to be some

unity. I am not only blaming Washington as some people do, and I am not only blaming the providers. We, as the consumers, feel that they are all just used to business as usual. You can't teach an old dog new tricks. But I say that habits are made to be broken. Just like people can stop smoking, they can stop doing business as usual, especially when it comes to human life. If we promise rural outreach, creative programming, developing trust, and changing attitudes, we need to become a family and make these things our basic values. We have to get the word out."

BEST COPY AVAILABLE

# HEALTHY START'S ENVIRONMENT: CAPITALIZING ON CHANGE

As Healthy Start sites enter their fourth year, the health care world is changing. Health care reform efforts at state and national levels took center stage in 1994, changing Healthy Start's place in health systems for women, children, and families. As this ground shifts, so, too, must the plans for sustaining the Healthy Start projects.

Changes continue not only in health care systems, but in other social services and welfare programs. All of these changes pose challenges to Healthy Start. However, Healthy Start programs have proved remarkably adaptable and quick to learn new systems. This chapter presents the new opportunities created by Healthy Start's changing environment.

In this chapter, the information about federal roles may soon be superseded, yet the suggested strategies for sustainability hold true. Although information about potential partners may become obsolete, the value of partnerships will not. To survive and thrive, community-based initiatives must develop networks, regardless of who has (or had) the resources. Projects that use these strategies to build relationships will be surrounded by support of all kinds. They will be well served by links with federal, state, and local resources, no matter how funding and political priorities shift.

## Changes in Medicaid: Medicaid and Managed Care

For many Healthy Start projects, Medicaid is a major source of funding. Medicaid often reimburses Healthy Start for services, and some projects contract directly with Medicaid to provide services such as case management.

Medicaid has been undergoing major changes at the state level, forcing Healthy Start projects to change, too. State Medicaid reform most often occurs under the auspices of a federal Section 1115 waiver, producing statewide Medicaid managed care systems. (Another type of Medicaid waiver affecting health care delivery in Healthy Start projects, the Federal Section 1915b waiver, is discussed later in this section.) These systems require challenging adaptations from Healthy Start projects, some of which create new opportunities.

## Section 1115 Waivers

Section 1115 waivers are granted for demonstration projects designed to help control costs and increase eligibility. A waiver exempts the recipient state from certain federal Medicaid rules, such as allowing variation in services across the state, waiving consumers' freedom of choice of provider, and mandating participants to join certain insurance plans, primarily managed care plans.

### *Many consumers and providers are affected by choice of provider 1115 waivers*

A choice of provider waiver limits the choice of provider for consumers insured by Medicaid. These systems are referred to collectively as "managed care." Managed care may work as a preferred provider organization (PPO), as primary care case management (PCCM), or as a heath maintenance organization (HMO).

*States with Approved Section 1115 Waivers as of 11/94*

- Arizona
- Hawaii
- Kentucky
- Oregon
- Rhode Island
- Tennessee

*States with Pending Section 1115 Waivers as of 11/94*

- Delaware
- Florida
- Massachusetts
- Missouri
- New Hampshire
- Ohio
- South Carolina

*States with Expected Section 1115 Waiver Applications as of 11/94*

- Illinois
- Minnesota
- Oklahoma
- Utah
- Washington

The trend toward managed care for Medicaid enrollees is evident through these large demonstration waivers. Growth in Medicaid managed care plans has been rapid in the past few years, from 6.3 million enrollees in 1992 to 8 million in 1994. Over 25 percent of HMO enrollees in the general population are under 15 years of age. They also constitute the largest percentage of those in Medicaid managed care plans.

***"Enrollment for Medicaid managed care soared between 1983 and 1992. In 1992, 6.3 million Medicaid enrollees were enrolled in managed care. In 1994, 8 million were enrolled."***

**— Peter van Dyck, Senior Medical Advisor, Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA)**

Although Medicaid managed care programs extend coverage to more people, they spend less per person. For consumers, this type of waiver may:

- Assure them of a regular primary care provider.
- Restrict access to providers by requiring a primary care "gatekeeper" referral to specialty care or hospital services. In this case, Medicaid patients must receive services only from a managed care provider.
- Limit access to traditional primary care providers such as Federally Qualified Health Centers or maternal and child health (MCH) clinics. This could limit access to culturally sensitive services and a range of facilitative services.
- Eliminate direct access to traditional providers for medical care or related services (e.g., substance abuse, mental health, AIDS home care).
- Restrict access to specialists.
- Make the enrollment process less responsive (because of language problems, inadequate information for plan/provider selection, or default enrollment process).

For providers, possible impacts include:

- Lock-out of provider networks (less of an issue for comprehensive primary care);
- Revenue loss;
- Lack of reimbursement to Federally Qualified Health Centers for services provided to patients enrolled with other providers;
- Disruption in referral patterns (e.g., specialists, substance abuse, mental health); and
- Lack of managed care contracts for public health departments to provide services such as immunizations, tuberculosis-related services, or MCH clinics.

The National Association of Children's Hospitals and Related Institutions (NACHRI) conducted a study in May 1994 comparing state Medicaid managed care plans. NACHRI found that most states neither require nor prohibit plans that contract with essential community providers. Healthy Start projects can work to ensure that these providers do not disappear.

For example, the New Orleans Great Expectations Healthy Start project has successfully established itself as a Medicaid provider, creating a more coordinated health care system for its clients. This strategy established an ongoing relationship with Medicaid and a mechanism for Medicaid reimbursement for Healthy Start services.

### *Healthy Start can encourage quality in managed care*

Healthy Start sites should be concerned about Medicaid managed care programs. To be involved, MCH, Healthy Start, and Medicaid must work together to develop states' waiver applications. The Public Health Service agencies have been working with the Health Care Financing Administration

> *"We can be vigilant on the federal side, but it does not substitute for up-front work at the state level."*
>
> — Peter van Dyck, Senior Medical Advisor, Maternal and Child Health Bureau, HRSA

to review these applications, but Healthy Start's involvement in the initial planning is crucial.

Participants in planning waivers must be specific regarding concerns and suggestions, emphasizing protocols, standards, contracts, and cooperation. Quality in managed care can be encouraged and monitored through protocols, contract language, and data monitoring.

Considerations for protocols:

- Immunization status
- Content for well-baby care and prenatal visits
- Outcomes of pregnancy
- Outcomes of family planning
- Appropriate and timely referrals for children with special health needs
- Appropriate and timely referrals for high-risk pregnancy
- Development of "marker" diagnoses (e.g., otitis media, asthma)

Considerations for contract language:

- Periodicity schedules
- Referral protocols
- Data requirements
- Performance standards

Considerations for data monitoring:

- Person-specific and encounter data
- Assessment of data quality
- Comparison with a fee-for-service care system
- Compatibility (ability to match or link with vital records and other public health data)
- Temporary sampling techniques

### *Healthy Start can integrate its services with Medicaid managed care*

Healthy Start and other community providers can cooperate with Medicaid managed care concerning:

- Immunizations

- Newborn screening
- Lead screening and treatment
- School-linked services
- Programs for infants with special health needs
- Outreach and public education
- Substance abuse treatment
- Mental health
- Head Start
- Special Supplemental Nutrition Program for Women, Infants and Children (WIC)
- Facilitative services

Healthy Start can consider including contract language concerning:

- Confidentiality
- Reimbursement
- Case management responsibilities
- Referral procedures
- Prior authorization

*"Medicaid managed care presents new and challenging issues of quality, data monitoring, and assurance. We must rise to meet the challenges."*

— Peter van Dyck, Senior Medical Advisor, Maternal and Child Health Bureau, HRSA

### *Expanding access requires a variety of strategies*

Although universal benefits would expand coverage, a more comprehensive strategy may be necessary to expand access. This includes expanding the number of available providers, not just changing financing and delivery systems. Some states, for example, have addressed these barriers through the

National Health Service Corps or through changes in malpractice laws. Facilitative services provided by Healthy Start, such as transportation, child care, and case management, are also a critical part of expanding access and utilization.

## Capitalizing on Changes in Medicaid: Managed Care and Healthy Start as Partners

Another vehicle for reform is the federal Section 1915(b) waiver, which excludes states from certain requirements including statewide implementation, comparability of services, and freedom of beneficiaries to choose a plan. These waivers give states less freedom to experiment than Section 1115 waivers and often are used to pilot managed care programs in local (rather than statewide) areas.

*States with Approved 1915(b) Waivers as of 11/94*

- Arkansas
- California
- Colorado
- District of Columbia
- Florida
- Georgia
- Kansas
- Kentucky
- Maine
- Maryland
- Massachusetts
- Michigan
- North Carolina
- North Dakota
- Pennsylvania
- South Dakota
- Utah
- Virginia

*(continued on next page)*

- Idaho
- Illinois
- Indiana
- Iowa
- Mississippi
- Montana
- New Mexico
- New York
- Washington
- West Virginia
- Wisconsin

***Healthy Start sites can obtain Medicaid reimbursement, but reimbursement may not cover intensive services***

Maryland, for example, has a 1915(b) choice of provider waiver. The program requires that Medicaid enrollees in Maryland choose either a managed care plan (an HMO) or a primary care case manager (PCCM). About half of Maryland's enrollees currently participate in the HMO option, the other half in the PCCM option.

Maryland's PCCM program carved out maternal and child health services, meaning that these services are a separate subset administered through separate mechanisms. To design this "carve-out," Maryland Medicaid worked with the state Title V agency and MCH advocates. These services are administered with the following special provisions:

- Women do not need referrals from their PCCM for prenatal care or family planning.
- HMOs are responsible for prenatal care, and work with the PCCM to provide Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services.

BIRMINGHAM HEALTHY START

- Targeted case management, home visiting, and nutrition counseling are included.

The Baltimore Healthy Start project participates in these programs. These services are reimbursed directly, even for those enrolled in an HMO. However, there are some pitfalls. Healthy Start services are often more intensive than those reimbursed through Medicaid. In Maryland, for example, Medicaid pays for three home visits, while Healthy Start conducts many more home visits. However, Maryland Medicaid is looking for ways to channel more funding to Healthy Start to support its intensive services. These efforts are likely to improve the chances for Healthy Start's sustainability.

### *Involving state entities in Healthy Start improves sustainability*

Healthy Start sites can involve Title V and Medicaid in their programs. Title V and Medicaid are potential partners in activities such as consortia activities and Fetal/Infant Mortality Reviews (FIMRs). Involvement in project activities builds relationships that can lead to Medicaid reimbursement for Healthy Start services and other funding opportunities.

For some Healthy Start projects, Fetal/Infant Mortality Review activities have been crucial to building relationships with Medicaid. Tragic cases documented by a FIMR committee can communicate the importance of social services to Medicaid. As a result, Medicaid may invite Healthy Start and local public health agencies to participate in its planning process.

Studies also suggest that managed care should collaborate on transportation, interpretation, case management, outreach, and patient education and information—all areas of expertise for Healthy Start. Healthy Start projects can be entrepreneurial by identifying their services that are marketable and potentially reimbursable through managed care entities.

### *Healthy Start can make contributions to the managed care environment*

Healthy Start is uniquely qualified to work in a managed care setting, because case management forms the basis of managed care. Other skills transferable to managed care include managing resources and living within budgets, without compromising quality. In addition, Healthy Start's expertise with low-income communities is valuable to managed care as it begins to serve this population. These Healthy Start contributions help meet managed care's goals of improving access, maintaining quality, and containing cost. Providing social services is an opportunity to develop programs that will bring in funding.

*"We know how to do [case management]. We provide many of the services involved. We are experts at this. We specialize in it; we do it every day."*

— Joan Savoy, Chief of Operations, New Orleans Healthy Start Project

### *Several steps are involved in becoming Medicaid providers*

The New Orleans Great Expectations Healthy Start project suggested the following steps to become Medicaid providers.

1. Become well informed about Medicaid and about managed care. Get copies of Medicaid regulations in your state. Learn the categories and where you fit in. Volunteer for committees and find out which are most important to your services. In New Orleans, Medicaid rules changed in 1994, and Healthy Start had to adjust. The project was able to place two case managers on the committee changing the rules. This helped keep the committee realistic and kept Healthy Start informed of coming changes.
2. Form alliances with those who can assist you. Learn who the players are and get to know them. Compare notes with experienced people.
3. Be creative and think through your plan before you proceed. It is more problematic to put together a plan you can't deliver, so be realistic as well as creative. To do this, seek staff input and get buy-in on your plans. Involve those who will implement your plan.
4. Write your implementation plan to obtain licensure and a Medicaid provider number. These are the requirements in Louisiana. No matter how your state does it, you'll need a system for documentation, follow-up, and tracking. Be sure to build on what already exists.
5. Train staff and pilot test your procedures. This helps prevent avoidable problems. Healthy Start staff must understand what is important and why. Be sure to provide staff with written information they can hold on to and refer back to.

6. Implement your program (after pilot testing and making needed adjustments).
7. Track client services and reimbursements. This will ensure that your claims are approved and paid. Develop an instrument for tracking client reimbursement over time and assign this task to a staff person.
8. Monitor and follow up. Be sure the system works, and make mid-course corrections.
9. Make program revisions/adjustments as necessary (when Medicaid rules change, for example). Be flexible. As one New Orleans staff member said, "Vigilance is the name of the game." At the time of the November 1994 Healthy Start grantee meeting, Louisiana was submitting a Section 1115 waiver, which will change the rules again.

## Capitalizing on Federal Resources

Healthy Start projects provide access to comprehensive services for their consumers, including family planning, violence prevention, substance abuse and mental health services, child care, family preservation, health care, and community development. Federal resources are available for each of these program components.

At the Healthy Start Grantee meeting, participants were informed of relevant federal resources and funding opportunities. Knowing these programs and keeping abreast of changes creates opportunities for Healthy Start to support program components and diversify funding.

### Family Planning Resources

Title X is the Federal Family Planning Services Program. Its goal is to give low-income women the resources to decide if and when to have children. Title X also takes into account the importance of preconceptional health care, identifying risks before pregnancy in order to plan for a healthy pregnancy.

In 1964, even as women were making gains in civil rights, 29 states still had laws prohibiting women's access to contraceptives. The Supreme Court found this unconstitutional. In 1968, federal funding was allocated to provide access to contraceptives for poor women through the War on Poverty program. In 1970, the Family Planning Research Bill became Title X of the Social Security Act.

Title X is currently administered by the Office of Population Affairs, U.S. Department of Health and Human Services. The funds are managed by the DHHS Regional Offices. Private nonprofit organizations or public organizations are eligible for these funds. Funding can be spent directly or distributed to contractors. Services provided under Title X must be voluntary and may not include abortion services.

In addition to contraceptive services, Title X also focuses on health maintenance through early detection of disease. Health services in family planning clinics usually include infertility diagnosis and treatment, cancer screening, and infectious disease screening.

In 1993, 4,200 Title X-supported clinics served 4.5 million women; 85 percent of the women served had incomes of less than 150 percent of the federal poverty level.

### *Family planning is crucial to Healthy Start's goals*

Family planning services are essential to reductions in infant mortality and improvements in the health of pregnant women. Healthy Start projects should link with Title X family planning services for a number of reasons:

- Title X services are the main source of reproductive health care for Healthy Start clients and others. More than half of Title X consumers are adolescents, women with incomes under 150 percent of the federal



BEST COPY AVAILABLE

poverty level, and African American women.

- For many, family planning clinics are the link to prenatal care. Family planning clinics are often the setting in which the health care provider confirms a pregnancy and refers the client to prenatal care. These clinics also help families learn the importance of spacing their pregnancies. Increasing the interval between pregnancies often improves the birth outcome and reduces the number of stressors to the family.
- Family planning is not just about preventing pregnancy, but about achieving wanted, healthy pregnancies. Achieving this goal would contribute greatly to reducing infant mortality.
- Family planning and Healthy Start are working toward the same goals: To reduce the number of unplanned pregnancies, and to increase access to health education, screening, and contraceptive services.

### *Healthy Start can leverage Title X resources*

Title X faced funding cuts of 40 percent during the Reagan and Bush Administrations, and has not yet recovered previous funding levels. The best way to leverage Title X resources, therefore, is to use Title X-funded agencies.

*"As Maya Angelou said: 'Anyone who can't be used is useless.' Use your Title X funded agencies. Learn our lessons."*

— Frank Bonati, President and Chief Executive Officer,
Family Health Council, Inc., Pittsburgh, Pennsylvania

- "Make us do things differently." Some Title X-funded agencies may have a "bunker mentality," developed when their funding was under attack. This mentality includes a fear of new things. Healthy Start programs can prod Title X agencies into change.

- "Use our experience and learn our lessons." All of these agencies may not provide perinatal care, but all of them have experience in providing reproductive care for at-risk women. At a middle school in Pittsburgh, for example, a family planning agency provides sexuality education classes taught by college students from the community. Title X agencies have lessons to teach concerning issues such as media relations, cultural competence, and age appropriateness.
- "Ask us to the table." Family planning agencies can help Healthy Start plan to maximize resources.

Healthy Start is relatively new; in comparison, family planning has been fighting for a network of care for at-risk reproductive-age women for many years. Healthy Start projects can capitalize on Title X's networks and experience as vital resources.

## Capitalizing on the Political Climate

*Family Planning advocates have created the following message for policymakers:*

*Do you want low-cost preventative care?*

*Do you want welfare reform (through reduced teen pregnancy)?*

*Do you want family values (making every child a wanted child)?*

*Do you want to save money?*

*Do you want to reduce the number of abortions?*

*Do you want to prevent infant mortality?*

*Saying "yes" to any of these is saying "yes" to family planning.*

## Violence Prevention Resources

The Centers for Disease Control and Prevention (CDC) has recognized domestic violence as a public health problem, and is instituting a strategic prevention response, the National Program to Prevent Violence against Women. This program, which can bolster Healthy Start's work, consists of five components:

- Surveillance (describing and tracking the problem)
- Research (increasing knowledge of causes and consequences)
- Prevention strategies that work (demonstrating and evaluating prevention strategies)
- Fostering of a network of prevention and support systems
- Support for a national communications network

Surveillance provides uniform definitions that help to identify the problem. CDC's surveillance efforts involve a number of initiatives:

- A national survey conducted by CDC's National Center for Injury Prevention and Control and the National Institute of Justice.
- The HMO study conducted in Albuquerque, New Mexico.
- The PRAMS/GA Reproductive Health survey, a collaborative effort between CDC and Georgia to add questions on domestic violence to Georgia's state survey.
- Cooperative agreements with state health departments in Massachusetts, Rhode Island, and Michigan. These projects are required to develop replication guidelines for use by other states.

Research efforts have included basic research through extramural research grants awarded in June 1994, and research agendas at CDC. Currently, CDC is conducting research to estimate the cost of intimate partner violence.

Demonstration and evaluation projects related to prevention strategies include:

- Extramural research grants.
- National Academy of Sciences study.
- CDC's evaluation agenda.
- University of North Carolina's Dating Violence Project focusing on community prevention for adolescent women.

- State surveillance systems.
- Four multifaceted community-based cooperative agreements demonstrating prevention strategies. These 4- to 5-year projects emphasize evaluation and replicability.

CDC also fosters a network of prevention and support systems. The violence prevention projects are in Chapel Hill, North Carolina; Duluth, Minnesota; Milwaukee, Wisconsin; Houston, Texas; and Douglasville, Georgia. Two of these projects address special populations: The Houston project focuses on preventing violence against pregnant and postpartum women, and the Douglasville project is a public awareness initiative called "Men Stopping Violence."

In addition, CDC supports a national communications network with a focus on information sharing and knowledge transfer. The network has three components:

- A national inventory of lessons learned in violence prevention, designed to help professionals in the field avoid duplication of effort
- Public awareness activities
- Education, training, and evaluation

### *Healthy Start can support families by asking questions about violence*

It is vital for health professionals who provide care to at-risk women to ask the right questions. Protocols encourage women to talk more openly about violence issues. Healthy Start is also vital to prevention efforts by helping women at risk to enter the system to help them handle violence if it occurs in their lives.

Although continuation funds for these CDC violence prevention initiatives are available only through FY 1995, the crime bill may lead to increased funding of prevention efforts in FY 1996–97. The bill authorized $4 million in 1996 and $6 million in 1997 for CDC to fund community-based violence prevention coalitions. These coalitions will promote public awareness and provide community education.

## Substance Abuse and Mental Health Resources

The Substance Abuse and Mental Health Services Administration (SAMHSA) is the newest agency in the Public Health Service. It was created in

October 1992, when the research institutes of the Alcohol, Drug Abuse, and Mental Health Administration were moved to the National Institutes of Health, making SAMHSA a service-focused agency.

SAMHSA consists of three centers—the Center for Substance Abuse Prevention (CSAP), the Center for Substance Abuse Treatment (CSAT), and the Center for Mental Health Services (CMHS)—in addition to the Office of the Administrator. The three centers manage the Substance Abuse and Treatment Block Grant, the Community Mental Health Services Block Grant, and several smaller demonstration and services grants.

### *SAMHSA makes women a priority*

SAMHSA had a mandate to create the Office for Women's Services, a policy office for women's issues. This office serves as the focus for women's issues, identifying issues and advocating for substance abuse services and mental health services for women. The office is mandated to ensure that the needs of women are met in a culturally competent manner.

The Office for Women's Services has two legislatively mandated projects. The first involves assessing the uniformity of data collected by SAMHSA on women's substance abuse and mental health services. The Office for Women's Services plans to develop a set of data standards for use by SAMHSA

programs, as well as a plan for implementing the data standards and making them available and accessible. The second project requires SAMHSA to establish, maintain, and operate a program to disseminate information about women's substance abuse and mental health services. Although funding has not been appropriated for this project, the Office for Women's Services is working with the three SAMHSA centers to build upon existing activities to develop a program for disseminating information about women's services.

### *SAMHSA's priorities include Healthy Start populations*

SAMHSA has identified six women's issues of priority (although funding is insufficient to thoroughly address these priorities). The six issues are:

- Physical, sexual, and emotional abuse. Although estimates vary greatly, 50 to 80 percent of women in treatment for substance abuse or institutionalized for serious mental illness have histories of physical or sexual abuse.
- Women as mothers and caregivers.
- Concurrent illnesses (e.g., substance abuse and mental illness). This focus area also addresses the relationship between substance abuse and primary care.
- Women with HIV, AIDS, sexually transmitted diseases, tuberculosis, and other infectious diseases.
- Women in the criminal justice system. These women are of special concern because of their growing numbers and because of the high incidence of substance abuse and mental health problems. Another concern is that these women might not be covered under health care reforms.
- Substance abuse and mental health issues for women as they experience the aging process. Special issues include prescription drug abuse and alcohol use.

SAMHSA also has funding priorities for target programs, including:

- Gender-specific and culturally competent services for pregnant and postpartum women and for women with dependent children. These two programs, the Residential Treatment Services Program for Pregnant and Postpartum Women (PPW) and the Residential Demonstration Treatment Grant Program for Women and Children (RWC), had funding available in FY 1995. Healthy Start projects were eligible for these funds.

- Emphasis on community-based and family-focused services (in conjunction with CSAP's Community Partnership projects).
- Evaluations (required for all projects, whether or not they are demonstration projects).
- Block Grant funding. Projects are encouraged to contact SAMHSA for the name of their state contact for these funds, since most states have opportunities for programs to compete for this funding. All states are required to spend a percentage of these funds on the pregnant and parenting population.

*"Develop the network, regardless of who has or had the money."*

**— Mary Knipmeyer, Associate Administrator for Women's Services, SAMHSA**

All of SAMHSA's federal collaborators have maternal and child health as a priority. Prevention of violence against women is a priority issue for the Clinton Administration. SAMHSA has had success in dealing with perinatal addiction, and is now expanding to address adolescents, women who abuse substances, women who are victims of domestic violence, and other populations. SAMHSA sponsors a Community Team Training Institute, which may provide an opportunity for Healthy Start to become involved in community planning around substance abuse issues.

## Child Development Resources

The Child Care Development Block Grant is administered through the Department of Health and Human Services, Administration for Children and Families (ACF). Linking child care with health is a priority for this Block Grant program.

The Block Grant became available in September 1991 to provide funds to help low-income families find and afford child care. It also aimed to improve child development services. This Block Grant does not require state matching funds. The grants go to all states, territories, and 221 Native American tribes.

Each state identifies a lead agency (usually the Department of Social Services or the Department of Education) to administer the funds directly or to manage the administration of funds through the community.

### *The Child Care Development Block Grant and Healthy Start serve the same families*

Four basic principles guide the Child Care Development Block Grant program:

- Parental choice of settings
- Access for those whose incomes are less than the state median income, and who are working or in school
- Access for children ages birth to 13 years (with the option to extend access to age 19 for children with special health needs)
- Priority for children with special needs and families with very low incomes

Child Care Development Block Grant funds are used for direct service, before- and after-school programs, and improvement in the quality of child care. Direct child care services are provided through such means as certificates distributed to parents. Providers are required to meet health and safety guidelines to participate. Seventy-five percent of funds not dedicated to direct service fund the before- and after-school programs. The remaining Block Grant funds go toward improving the quality of child care, including training, technical assistance, referral centers, parent education, start-up funds, help in meeting health and safety standards, and increases in salaries for child care staff. This funding is flexible at the state level.

The program works to protect children and promote their health through a two-generational approach, focusing on the health needs of both parents and their children. These child care services and Healthy Start programs are serving some of the same families. Several Healthy Start sites collaborate with

*"Together we can maximize our resources. Let's link!"*

— Moniquin Huggins, Child Care Program Specialist, Child Care Bureau, Administration for Children and Families

their states' child care agencies. Healthy Start projects can contact their state's lead agency for the Child Care Block Grant funds to begin collaborating.

## Maternal and Child Health Resources

The Maternal and Child Health Bureau is funded at just under $700 million per year. Eighty-five percent of this money goes to the states as a Block Grant, distributed by a formula depending on state population and percentage of children in poverty.

Since 1989, state application and needs assessment requirements have been more rigorous. The state's application is more meaningful, and the accountabilities attached to the funding are more stringent. In addition to an annual application, a comprehensive statewide needs assessment covering all mothers and children in the state is required every five years. The state needs assessment should be an aggregate of each of its communities' needs assessments.

### *Systems development is a priority for Title V funds*

Direct services are less of a priority for most states' Title V Block Grants. The funding is earmarked for "improving the health of mothers and children"—this may not necessarily require more direct services. A synthesis of services may be needed, and Title V funding has the flexibility to do it. However, Title V funds have traditionally gone to service delivery, and it may be hard to move toward systems development without any new funding. One hope is to leverage Medicaid funds to pay for direct services.

States must conduct their five-year needs assessments in FY 1996. The needs assessment and five-year plan, submitted July 15, 1995, will identify the problems and determine the program planning for the next five years. The

*"Use your state MCH contact, and be sure the needs assessment plan is meaningful and makes sense."*

— David Heppel, Director, Division of Maternal, Infant, Child, and Adolescent Health, Maternal and Child Health Bureau

legislation guiding this process requires public participation in developing the plan. This public participation is Healthy Start's entree into Title V planning to encourage statewide implementation of Healthy Start strategies and lessons learned.

### *MCHB and the Administration for Children and Families are connecting health and family welfare*

The Maternal and Child Health Bureau works with other organizations, since it has a small budget. MCHB works with CDC on injury and violence prevention, for example, and with SAMHSA on a perinatal substance abuse initiative.

One major collaborative initiative is the Family Preservation and Family Support (FP/FS) work with the Administration for Children and Families.

Family support refers to prevention initiatives to keep at-risk families together by helping them function better. Family preservation refers to efforts to put families back together again. ACF plans to keep a focus on family preservation, yet knows that prevention is necessary. ACF has reached out to other agencies to coordinate and collaborate in efforts to implement the new Family Preservation/Family Support Block Grant.

In an effort to integrate health services into FP/FS services, MCHB provided funding jointly to state MCH and child welfare agencies to improve the plan for FP/FS funds. States had to apply for the funding, showing how MCH

*"I have watched Healthy Start struggle to begin, grow and move forward, confront complexities, and meet success. Using creative and traditional approaches, Healthy Start has built a sense of community purpose and vision."*

— David Heppel, Director, Division of Maternal, Infant, Child, and Adolescent Health, Maternal and Child Health Bureau

interests would be represented in FP/FS planning. The application, requiring the signatures of both the MCH and the child welfare agency directors, must (1) focus on integrated community systems that include at-risk pregnant women and children with special health needs; (2) emphasize primary prevention; and (3) include home visiting as a significant component—all elements that describe Healthy Start.

## Community Development Resources

### Empowerment Zones and Enterprise Communities

#### *Like Healthy Start, EZ/EC takes a holistic approach*

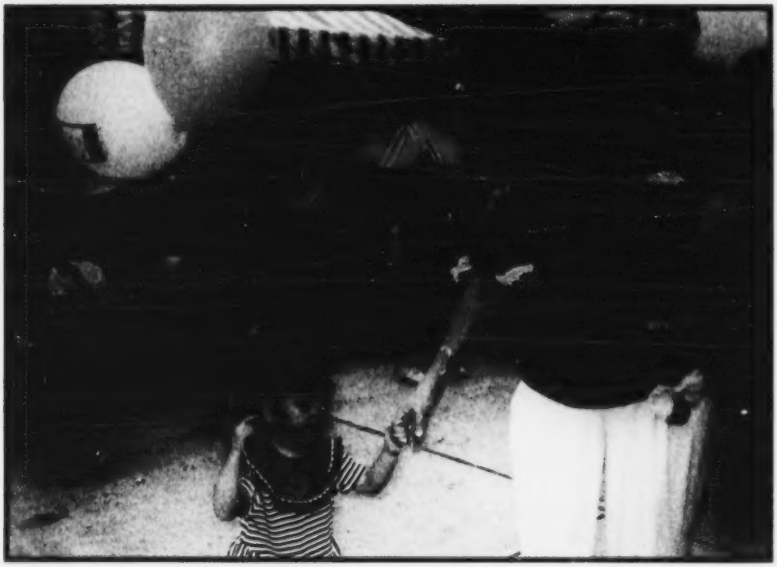
The Empowerment Zones and Enterprise Communities (EZ/EC) Program is unique because it was designed specifically to address human, physical, economic, and development issues in context together. The Office of Economic Development strongly encourages this approach at both federal and local levels. Moreover, the program requires community partners who applied for designation status to conduct a community needs assessment with neighborhood residents and groups.

This program has a history dating back to the early 1980s, when the program proposed in Congress was called Enterprise Zones and relied primarily on tax incentives to encourage businesses to invest in distressed areas. The program evolved when Putting People First, a campaign initiative stressed by President Clinton, bridged human, physical, economic, and developmental issues.

The current Empowerment Zones and Enterprise Communities Program was established as part of the Omnibus Budget Reconciliation Act of 1993, and President Clinton announced at that time that 104 designations would be awarded. These designations would be made through the Department of Housing and Urban Development for urban areas (six empowerment zones and 65 enterprise communities) and through the Department of Agriculture for rural areas (three empowerment zones and 30 enterprise communities).

#### *EZ/EC helps communities develop*

Incentives for empowerment zones include tax incentives for businesses to either relocate or expand in the designated zones in order to create economic opportunity for neighborhood residents, as well as tax-exempt financing. There will also be increased access to over $1 billion of DHHS Title XX social service block grants. For the zones designated by the Department of



PEE DEE HEALTHY START

Housing and Urban Development in urban areas, this funding amounts to $100 million for each of the six zones. For the zones designated by the Department of Agriculture in rural areas, the funding amounts to $40 million.

Incentives for enterprise communities include new tax-exempt financing and eligibility for $2.9 million through Title XX. The Title XX funding is to be transferred from the federal government to the states, and from the states directly to the designated zones or communities to carry out their respective strategic plans. In addition to the specific funding that flows from this designation, other federal initiatives have been alerted to the program and have been challenged to identify additional funds or technical assistance resources that can be allocated to the designees.

More than 500 applications were received. The review teams evaluated applications using four key principles: economic opportunity, sustainable community development, community-based partnership, and strategic vision for change. The Community Enterprise Task Force, led by Vice President Gore, will coordinate supportive activities.

Seventeen of the 22 Healthy Start sites are located within the newly designated Enterprise Communities and Empowerment Zones. This is a very positive reflection of the collaborative environment Healthy Start has seeded in these communities.

## Americorps

### *Americorps focuses on communities*

The National and Community Service Trust Act of 1993 established the Corporation for National Service. The mission of the corporation is to engage Americans of all ages and backgrounds in community-based service. Americorps is the "flagship" of the Corporation for National Service. Currently, more than 300 programs are in place, and hopefully, more than 20,000 people will soon be participating.

The Americorps program hopes to have an impact in three areas:

- Community service, by providing direct and demonstrable benefit to the communities where Americorps participants are working
- Community partnerships, by strengthening the partnerships between individuals and institutions to better address the needs of communities
- Americorps participants, by enhancing ethical and professional development through education, training, and service

Americorps participants work either full time or part time. Full-time participants receive a living allowance of $7,640 per year and an educational benefit of $4,725 per year. Full-time participants are also eligible for health care and child care coverage. Part-time participants receive approximately half the allocation for living allowance and educational benefit; they are not eligible for health care or child care coverage.

### *Americorps priorities match Healthy Start's goals*

In 1994, priority areas of service included:

- Health and human needs: independent living assistance, community-based health care, rebuilding neighborhoods
- Education: school readiness, school success
- Public safety: crime control, crime prevention
- Environment: neighborhood environment and natural environment

The priorities have expanded somewhat in FY 1995 to include services such as early child development, community policing, victim assistance, neighborhood and environment, and school success.

### *Americorps resources are targeted to show impact*

Ideally, Americorps hopes to place a minimum of 20 full-time participants in a given community to achieve the goal of demonstrable impact. One

of Americorps' goals is geographic (rural/urban) diversity among participating communities. Cultural diversity among participants is another important aspect of the program.

Two-thirds of Americorps dollars are directed to the states and each state has a Commission for National Service. The remaining third is retained by the Corporation. Americorps fared well in FY 1995, with appropriations of $250 million (a 60 percent increase over the FY 1994 appropriation of $160 million).

Criteria that affect grantee selection include quality of programming, sustainability, innovation, and replicability. No more than 5 percent of funds to a grantee can be used for administrative costs. The Corporation for National Service covers 100 percent of the child care costs for participants and up to 85 percent of the health care allowance and the living allowance; grantees are expected to provide a 15 percent cash match. The Corporation also covers up to 75 percent of program operating costs (with grantees providing a 25 percent cash match or in-kind service). The Corporation will pay for relocation of Americorps participants in cases of hardship.

### *The Health Resources and Services Administration's Community Care Corps focuses on health needs*

The purposes of this program are to:

- Improve access to comprehensive primary health care through home and community-based services;
- Develop participants in civic, educational, and professional areas through preservice and in-service training, mentoring, and service delivery; and
- Strengthen communities to address their unmet health care needs.

The Health Resources and Services Administration (HRSA) Community Care Corps, a subdivision of Americorps, has placed 95 participants in three Healthy Start sites (Pittsburgh, Chicago, and Cleveland). Some of the participants (the community health workers) are residents of the community who have earned a high school diploma or GED (or made a commitment to do so). Other participants are students who have been admitted to a health professions school. All participants must be 18 years of age or older.

HRSA's partners in this initiative include the Corporation for National Service, primary care health service sites (such as Community Health Centers, Healthy Start sites), health professions schools, community organizations, state/local health departments, U.S. Public Health Service Regional Offices III and V, and HRSA Community Care Corps participants.

## CONSUMER VOICES

*Lillian Armstrong, Baltimore Healthy Start*

As a senior neighborhood health advocate for the Baltimore Healthy Start project, Lillian Armstrong provides outreach services to bring women into prenatal and well-child care. She was initially recruited as a client with Healthy Start's predecessor program, The Baltimore Project. At that time, Ms. Armstrong was pregnant and very concerned about the health of the baby because she had lost two babies to sudden infant death syndrome (SIDS). The Baltimore Project offered her support and assistance throughout her pregnancy. Her son, Andre, was the first baby born into The Baltimore Project; today, he is a healthy five-year-old. Ms. Armstrong is a homeowner through the Habitat for Humanity program. These are her words.

"I was 29 years old and pregnant. I was scared because I didn't know anything about sudden infant death—no doctor told me anything about

BEST COPY AVAILABLE

why my children died. I was really scared and I said that I didn't want this baby. So, one day a woman from The Baltimore Project was outside, recruiting, and she said that I was the first person she had seen all day. I said that I would go see what this program was about. I got up there and wouldn't tell them all my information because I was scared. I didn't know who to trust because I used to tell my family members things and they just 'ratted' it all out. So, I started going and I felt like I could trust these people. I started talking and kept on talking. They gave me tokens to go to the clinic, so I kept on going.

"Then it was a Sunday, and I fell down in the bathroom. I was really scared because I wasn't supposed to have the baby until December. I said to myself that I must be getting ready to have this baby. I didn't know who to call, so I went on to the hospital and they wanted to stop the labor. Well, I couldn't let them stop it; if it was going to come, it was going to come. When my baby came, he weighed 8 lb. 11 oz., and I was still scared because I didn't know what to do. If I took this baby home like I took the other two babies home, he was going to die. I talked to another doctor, and he said, 'Ms. Armstrong, I will give you a heart monitor and I'll teach you CPR.' I said 'okay,' and I took my baby home. I didn't get much sleep because I was scared. I wasn't going to let this baby die on me, not again. If this baby was going to die on me, I was thinking I might as well go down myself.

"I also had my other three children and I used to yell at them that they were making too much noise, especially when the baby was sleeping. I went around thinking that I needed someone to talk to because I felt myself going a little crazy about this baby. They told me if it was meant to be, it was meant to be. I began to go to church and pray. When I went to church, people there started talking to me.

"Then, as the baby got older (at six months he weighed 26 pounds), the doctor said that we could take the monitor off of him. They studied him for sudden infant death syndrome at University Hospital. I was so happy and relieved, and I finally got some sleep. I kept going around to The Baltimore Project and they asked me if I would volunteer. I said I would, because I wasn't doing anything else because my children were in school all day. So I kept on going and going. One day they asked me if I would like to work there. I said, 'Sure.' I guess I was scared, coming from

one side of the tracks and going to the other side. But I thought I could try and just kept going back.

"Then they gave me some clients. I was scared because this was my first time going out, knocking on doors, and recruiting someone for the program. I met this girl and she really liked me. She asked if I was going to come back and see her the next day and I said, 'Yeah, I'll be back tomorrow, baby.' In my work, I take them to the clinic, I give them food, Pampers, milk. If I can't find any, I even give them food out of my refrigerator because no one knows what it feels like if you are hungry and you are pregnant, when you have no one you can count on, when the father isn't there. I've been through it and I know what's going on.

"I used to live in a house with four or five other families there and some were drug users. I've been through it all. They would take from you. I understand what these girls are talking about when they tell me how they feel. I can't tell anybody else except for my case manager. She tells me not to get upset and that we will find a way to help. I give the girls my home phone number so they can call me at home.

"Only God knows what we go through when we are out there on the streets. Sometimes we have to run, or duck and dodge bullets. Sometimes, I'll be in a room where the girl and her boyfriend are fighting and I know it's not my place to tell him that he can't hit her. It's a long road. You have to knock on doors, knowing that lots of them are going to get shut in your face. So, you go back out there and try again. I have a 13-year-old who is scared to tell her mother that she's pregnant. I know I can't do that for her. I have a 16-year-old, she's in 11th grade. I think that I wouldn't want one of my children to be pregnant, but I still have to love her, and the baby, too. That's what I tell her mother. I tell them all that the first thing they need to do is go to the clinic and not wait until they get big, and then tell their mothers because they will be heartbroken. I tell you, it's a road.

"I live in a community where drugs are sold, sometimes right in front of your house. If you ask them to move, they tell you to make them move. Nobody should have to live through any of this. I ask the people to get together, get the community to try to stop them, but everybody is scared. It's just tragedy."

BEST COPY AVAILABLE

# EVALUATING IMPACT: TELLING THE HEALTHY START STORY

*"The results that I'm talking about are holistic results, not just looking at the numbers based on the medical model, but looking at how much help the holistic situation received—the family, the mother, the father, the other children."*

— Joseph Reid, Director of Grants Development, City of Atlanta

Local evaluation is the vehicle for learning from each project and all its participants. Healthy Start local evaluations capture the processes and outcomes that are Healthy Start. Sites have learned lessons from their local evaluations that improve their programs, improve community involvement, and help tell the Healthy Start story.

In keeping with their philosophy, Healthy Start sites have involved their communities in evaluation. Community members are involved in improvements in data collection, data analysis, and program design, in response to evaluation findings. Community involvement and decision making are needed

here as in other parts of governance. Through community involvement, the project and the community learn Healthy Start's lessons together.

Each Healthy Start site, like each community-based initiative, has a unique set of locally relevant components. Although components across projects may be similar in focus, they are designed to best serve their particular community; thus, they are as diverse as the communities served. All of the communities, however, struggle with some similar evaluation issues, especially with respect to what data should be collected and how the data should be collected.

## Collecting Evaluation Data at the Community Level

Although each Healthy Start site has many different elements, the projects have evolved to include a common core of facilitative service activities: case management, outreach, transportation, housing, substance abuse services, and education. One tenet of research is that evaluation must reflect what the program aims to accomplish. In keeping with this principle, evaluation of Healthy Start's support service activities must be creative and flexible. The following examples illuminate the strategies, successes, and challenges of local evaluation in Healthy Start.

### *Local evaluation data describe the consumers and the services they actually use*

The New York Healthy Start site has been developing simple data collection tools for contractors who provide a variety of services. The site uses a survey developed by Healthy Start staff to collect basic demographic and service-specific information. The demographic information helps Healthy

*"Support services require different evaluation methods. We are willing to settle for less information in order to get valuable information."*

— Cheryl Merzel, Director of Evaluation,
New York Healthy Start

Start determine whether it is truly reaching its target population, while the service-specific questions are tailored to the service provided (e.g., after-school services, transportation, literacy programs). Data collection also focuses on tracking the complete referral networks, since creating these networks is a program goal.

### *Evaluation requires a model describing which factors affect outcomes and how to measure those factors*

The Baltimore Healthy Start site has allocated funding to 18 medical providers in the community to make their services more user-friendly. This strategy assumes that an increase in the use of services will lead to better outcomes. Improvements include better or expanded hours, child care, and improvements in the physical setting.

Evaluation of this project focuses on measuring utilization rates and examining client satisfaction. Baltimore Healthy Start conducts five-minute telephone interviews with a sample of women who have received services. The interviewer asks questions relevant to Healthy Start objectives that are believed to lead to improved outcomes. The project has begun to analyze the data.

*"We implement reforms based on the assumption that increased utilization should lead to better outcomes. Our evaluation system must support this theory."*

— A Baltimore Healthy Start Representative

### *The data should benefit those who collect it*

The New York Healthy Start project was careful to develop tools that would be useful to the providers as well as to Healthy Start. In this way, the evaluation serves not just as a Healthy Start program monitoring tool, but also as a monitoring system for lead agencies. Some providers have needed more assistance with the data collection system than others; some have automated systems, while others have very small staffs and no computers.

Reflecting the comprehensiveness of the providers has been a challenge. Healthy Start funds a small portion of these agencies' services, yet clients have access to all of the services in the project. One way of resolving this is to encourage recording of in-house referrals. The program also interviews providers for qualitative data, creating a comprehensive picture of the services provided.

### *Information about male partners can be difficult to collect*

For many sites, support of male partners is an important component of Healthy Start. Information about male involvement is tricky to obtain, since male partners might not sign attendance sheets or other forms. Sites frequently rely on case managers' reports to collect this information.

*"The existing system gives the illusion of men not being involved."*

— A New York Healthy Start Representative

New York Healthy Start is one site that has experienced problems in getting information about male partners. Asking women about their male partners has implications for eligibility for benefits such as Aid to Families with Dependent Children (AFDC) and Medicaid. It may be necessary to keep information about male partners anonymous in order to avoid jeopardizing consumers' benefits.

Sites with specific program components for male partners have more access to such data. Baltimore Healthy Start, for example, collects information about male partners through men's services provided in the Healthy Start centers and through a series of interviews with women, including questions about male involvement in child care. The project has used a number of mechanisms to collect these data. As in other areas, these data require creative collection and multiple methods to be complete.

*"Go to the source. Speak to men at the clinic. We made our Young Fathers' Clinics culturally diverse and male friendly."*

**— A Newark Healthy Start Representative (referring to Young Fathers' Clinics funded by Healthy Mothers, Healthy Babies, which the Newark site plans to incorporate into its Healthy Start project)**

### *Involving community members in data collection has benefits for the research, the project, and the community*

A centerpiece of the New York site's evaluation effort is the ethnographic analysis of New York Healthy Start's three distinct and diverse communities. Conducted by a team of ethnographers, the study assesses community development, examining Healthy Start's contribution to community infrastructure. The ethnographers are residents of the communities and were chosen with input from these service areas. Focus groups with case management clients, interviews, document review, and other data collection methods are being used to document Healthy Start's impact on the communities. This approach captures a richness of data, building on the interrelationship of the information gathered.

*"Numbers don't tell you enough."*

— Cheryl Merzel, Director of Evaluation,
New York Healthy Start

The Baltimore Healthy Start site also is using qualitative data to evaluate community development. The project is interested in the impact of the Healthy Start one-stop service center models on the communities. The research team includes community members who advise those collecting and interpreting the qualitative data. Methods include community mapping, key informer interviews, and focus groups.

In Chicago, Healthy Start has developed a class at DePaul University, offered to undergraduates and to residents of the Healthy Start communities in Chicago. The class pairs an undergraduate with a community member to interview within the community. College credit is granted to those who complete the course, which is free to community members. Like New York, the Chicago project has found the community members' participation in evaluation to be an advantage in collecting and interpreting data. An additional benefit is the job training provided to the community members involved.

## Evaluating Consortia and Governance within Healthy Start

Recently, increasing emphasis has been placed on evaluating outcomes. For Healthy Start, however, evaluating process may be just as important.

*"How do we evaluate processes in Healthy Start? Specifically, we have asked: What ways did the problem-solving activities of Healthy Start change over the duration of the project?"*

— Nathalie Vanderpool Bartle, Evaluation Manager,
Philadelphia Healthy Start

Because Healthy Start is built on community involvement, examining the processes for achieving this goal is crucial.

### *What are the structure and principles being evaluated?*

The Philadelphia Healthy Start project has a governance structure of guiding principles similar to those of other Healthy Start sites. These guiding principles specify that the consortium must consist of community-based organizations, maternal and child health providers, consumers, and concerned residents. Philadelphia Healthy Start has worked to keep a balance of members on the steering committee, in the work groups, and at all levels.

Philadelphia Healthy Start's governance consists of a steering committee and an executive committee, in addition to the Healthy Start consortium. An evaluation was guided by the consortium's collaboration work group.

### *To evaluate, the sites needed to define the components of consortium development*

Cleveland's Healthy Start staff have distilled from the literature the central components of consortium development:

- Leadership
- Membership
- Strategy
- Structure

- Systems
- Task
- Environmental linkages
- Purposes

Defining these elements allows the Healthy Start sites to analyze the components of consortium development and examine how each component has contributed to collaboration.

> *"Ultimately, to whom is governance accountable? To Healthy Start, to itself, and to the community."*
>
> — A Healthy Start Representative

### *Sites use evaluation methods that fit their programs*

A wide variety of evaluation methods have been employed by Healthy Start sites. Boston has conducted interviews and Cleveland has used research methodology for evaluation. Oakland is using an approach that incorporates both quantitative and ethnographic analysis.

Philadelphia's Healthy Start evaluation is conducted on several levels. It includes survey questionnaires, focus groups, collected data from minutes of meetings, and records from the various work groups to assess collaboration. Philadelphia's primary evaluation tools consisted of a comprehensive survey and a focused survey administered to Healthy Start consortium members. The comprehensive survey was conducted in summer 1994, and the first round of focused surveys was completed in fall of that year.

### *Evaluation findings drive program improvements*

Philadelphia Healthy Start learned about successes and challenges through survey findings (FY 1993–94, N = 85). Following is a brief summary of responses to key issues.

What's going well in the Philadelphia Healthy Start Consortium?

- Participants feel involved in the decision-making process.

- Participants feel that power is shared in groups.
- A diverse group of participants are committed to the project.
- Opportunities have been created for networking among colleagues and agencies.
- A better understanding of problems has been achieved.
- Participants are empowered to develop strategies to address needs.

What needs attention in the Philadelphia Healthy Start Consortium?

- Participants need a better understanding of Healthy Start's mission and goals.
- Participants need a better understanding of work group goals.
- Communication needs to be improved among all Healthy Start groups.
- Strategies need to be to developed to encourage consistent attendance at meetings.
- The amount of paperwork and number of meetings need to be reduced.
- New participants need to be recruited to represent all stakeholders.

The Philadelphia Healthy Start site is finding ways to evaluate the progress of collaboration and incorporate feedback. Philadelphia's Healthy Start site, for example, employed 10 staff members initially. This number was reduced to five, with each staff member assigned to one of the five work groups focusing on a specific goal. Responding to evaluation findings that the five groups worked too independently, these work groups now function as an organized whole. This ensures that the project is progressing toward its identified priorities. The Philadelphia site views feedback as a valuable learning process and expects to have reliable data about consortia functioning.

### *Evaluating collaboration means finding out what partners bring to the effort and what they take away*

Community agencies involved in collaboration are not simply concerned about reducing infant mortality. Sites integrate partners' goals with Healthy Start goals to build a common agenda. This process touches on ownership, power, and priorities at many levels.

*"Community involvement is of critical importance—not just for the five years of Healthy Start, but beyond this time as well."*

— Nathalie Vanderpool Bartle, Evaluation Manager, Philadelphia Healthy Start

One particular difficulty involves asking community members to participate in a consortium when reduction of infant mortality may not be their most immediate need. Members of the community may be more concerned with basic needs such as housing, food, or clothing. Consortium members must continue to receive feedback on the program in order to continue building links among stakeholders, particularly the community.

### *Marking changes in consortia over time helps tell the Healthy Start story of community involvement*

Evaluating consortia over time illuminates their developmental processes. Projects tend to shift with respect to where they may have been in the beginning, at the midpoint, and at the end, and this speaks volumes about the unique stories of each site in joining forces with the community.

## Evaluating Public Information and Public Education Campaigns

Healthy Start sites use public information and education to increase knowledge and to recruit clients, and thus help to reduce infant mortality in their communities.

### *What are the goals and strategies being evaluated?*

The goal of the Baltimore site's Public Information Campaign (PIC) is two-fold: (1) Educate clients, service providers, local companies, and others about infant mortality; and (2) motivate these same target populations to think about how they see themselves contributing to the resolution of the problem of infant mortality. The Baltimore site has many strategies to meet this goal, including health fairs, literature distribution, outreach, informal polling, random "spot" household surveys with Healthy Start participants and other community members, and public service announcements.

### *Concerted evaluation efforts are the only way to identify the impact of public information*

Evaluating efficacy is vital to information and education campaigns. Baltimore Healthy Start, for example, produced a series of public service announcements (PSAs) with the well-known female rap group, Salt-N-Pepa. The staff believed these women would be effective spokespersons because the community could relate to them. The three African American women in this group are single mothers and natives of the Baltimore area.

In order to test the effectiveness of these announcements, Baltimore Healthy Start surveyed callers to a state toll-free phone number aired with the PSAs, enabling staff to count the number of calls generated by the PSA. The Baltimore site developed a written form for state employees who staff the toll-free number, so they could obtain more detailed information about the callers and their individual questions, needs, and understanding of Healthy Start. These data will allow Healthy Start to analyze the audiences reached and the message received.

### *Longitudinal analysis is needed to measure changes in knowledge throughout the community*

Baltimore Healthy Start performs longitudinal evaluation using surveys administered during dissemination of information. The surveys are conducted

with Healthy Start participants as well as nonparticipants within the Healthy Start neighborhoods. The survey asks, for example, whether the individual recognizes Healthy Start literature and/or educational materials, or whether the individual knows where the Healthy Start office is located. These surveys are conducted regularly and may be repeated with the same households to determine change over time.

The Baltimore area offers similar, competing programs that provide public information. It has been critical for the Baltimore Healthy Start site to tailor its evaluation efforts to address only those events, public service announcements, and educational materials unique to the project.

### *Evaluation helps design public information campaigns tailored to the community*

Oakland Healthy Start, relying primarily on survey data through its evaluation process, found that clients came not because of its initial public information campaign strategy, but because of recommendations by trusted friends in the community. The Oakland project had recruited a noted African American movie actor and director to appear in a series of billboard announcements. These billboards replaced cigarette and alcohol advertisements in Healthy Start communities. Evaluation activities revealed that many people in the community did not recognize the celebrity or did not see him as a motivating figure. With this valuable information, the Oakland project has reinvested in more outreach-centered initiatives with community members.

### *Evaluation supports innovations to meet Healthy Start's public education goals*

Healthy Start sites continue to pursue new and creative ideas to meet their public education goals. Public information campaigns must tap into the community's unique structure, culture, and symbols. Continuous evaluation of messages and methods is the only sure route to effectively informing and educating the public.

## Evaluating Prevention Services for Adolescents

Prevention services for adolescents are a challenging component for many Healthy Start sites. Services to adolescents raise a number of issues:

- Lack of positive role models and supportive families for adolescent mothers
- Relationships between risk factors for adolescent pregnancy and those for infant mortality
- Difficulties in obtaining parental consent for provision of services to adolescents
- Relationships with schools, a crucial link in providing school-based services
- Difficulties in reaching adolescents who do not attend school
- Importance of focusing on educating young men as well as young women

*"We need to make sure that our strategies meet adolescents where they are and give them what they need."*

— A Healthy Start Representative

### *National models and research inform program development and local evaluation*

Evaluation must meet the standards in the field to be valuable. Building on preexisting interventions that have been tried over time with different groups of adolescents helps make program design and evaluation credible. Interventions for adolescent populations beginning early in development (by middle school) and using rigorous outcome measurements are favored.

Evaluation instruments must look at baseline attitudes and behaviors. For pregnancy prevention, outcome measurement must continue for at least 12 months beyond the intervention since posttest measures are not always reliable.

*"The long-term impact is crucial since adolescents might say or do one thing now, when the real question is: How long will this effect last?"*

— Karen Thiel Raykovich, Director, Healthy Start Evaluation, Office of Planning, Evaluation and Legislation, HRSA

***Numerous resources are available to help projects build on existing knowledge***

Adolescent pregnancy prevention is a much-studied topic. Many resources are available to assist community-based initiatives in designing and evaluating this component. Following are some examples:

- The Institute for Health Policy Studies at the University of California, San Francisco, is evaluating prevention and care services for Healthy Start adolescents as well as the service barriers that exist. In conjunction with this work, Mathematica Policy Research, Healthy Start's national evaluation contractor, will analyze the experiences of Healthy Start's adolescent clients, using the Healthy Start Initiative's national evaluation data.
- Sociometrics, Inc. has a synthetically developed data set on pregnant and parenting adolescents and teenage pregnancy rates to compare to client outcomes. The firm is also developing a data archive on adolescent pregnancy prevention outcomes. [For information on these evaluation methods, see Evaluating Adolescent Pregnancy Prevention Programs (Sage Publications), edited by Josefina Card and Brent Miller.]
- The Sexuality Information Education Center of the United States (SIECUS), based in New York City, has a resource library of adolescent pregnancy prevention curricula.
- Douglas Kirby completed work for the Centers for Disease Control and Prevention on a meta-analysis of prevention services, based on the current literature.

- Lorraine Klerman and colleagues have conducted a 20-year follow-up study, with promising findings, concerning outcomes of care given to pregnant adolescents in New Haven, Connecticut.
- The Robert Wood Johnson Foundation has information on school-based health services. Data sets are available for evaluation of school-based clinics.

Through years of studying prevention initiatives, the field has refined its approach to prevention of adolescent pregnancy. Experts now favor prevention curricula that promote abstinence combined with a family planning perspective to lower the risk of pregnancy.

## Evaluating Economic Development, Community Revitalization, and Empowerment Initiatives in Healthy Start

Economic development often is viewed as the most influential contributor to community revitalization and empowerment, because Healthy Start communities are generally low-income communities. All Healthy Start sites have developed programs that aim to teach how to become self-sustaining. In addition, Healthy Start projects have helped establish the linkages and partnerships that have improved economic conditions and quality of life—not only within the communities served, but also within their cities and states. The challenge is to perform evaluations that represents the true impact of these programs.

### *Economic development initiatives come in many forms*

Economic development efforts work to bring new resources into the community in the form of revenue, employment, services, and products. These efforts rely on the following strategies:

> *"We must teach the consumers 'to fish,' rather than give them a fish."*
>
> — Reverend Robert Dye, Pittsburgh Healthy Start [paraphrasing the old Chinese proverb: "Give a man a fish and you feed him for a day; teach a man to fish and you feed him for a lifetime."]

- Entrepreneurship, both formal (growing small businesses) and informal (building on bartering)
- Local businesses as employers
- Public contracts, federal set-asides for residents (through HUD, for example)
- Institutional reinvestment in communities (through banks, savings and loan institutions, federal funds)
- Community revitalization through organizing neighborhoods (through neighborhood watches, clean-ups, park reclamation)

Healthy Start sites have pursued all of these strategies. They have found that creating partnerships with other groups via task forces, committees, collaboratives, linkages, or outreach is vital to enhancing the success of economic development initiatives. Sites have been challenged to prioritize their economic development strategies because of limited resources among collaborating agencies and within the target communities.

### *Evaluating the impact of economic development issues is challenging*

Although Healthy Start staff take pride in these initiatives and feel confident that they enhance Healthy Start's sustainability, identifying evaluation methods that support these successes is challenging.

Sites have expressed concern that they are using superficial criteria to track successes of individuals who benefit from economic development. Local evaluators have significant anecdotal data but are struggling to analyze this information in ways that examine community impact and its relationship to Healthy Start efforts. Both process and outcome evaluation are critical, and short-term and long-term indicators of change must be incorporated into evaluation approaches.

Evaluation must demonstrate program viability and the positive impact of services on the community. Challenges to the evaluation process include the following:

- Developing long-term and short-term outcomes
- Selecting appropriate indicators (e.g., job referrals, placements made, linkages established, businesses started, sustainable long-term placements)
- Choosing the unit of analysis (individual, family, system)

- Attributing impact to individual program interventions
- Allowing sufficient time for economic development initiatives to mature before evaluating results

The unique character of each site and its diverse struggles must be illustrated in the evaluation of economic development and community empowerment. As sites struggle with these challenges, they are devising evaluation tools that include anecdotal, narrative, and other qualitative data items.

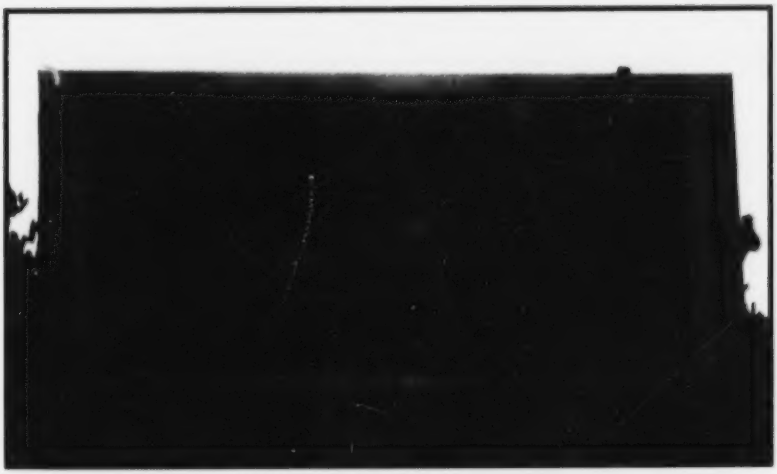
### *Community coordination is a marker of success*

The New York Healthy Start site has coordinated diligently with other local agencies to create a common agenda for economic development, using the services of existing public and private economic development programs to maximize opportunity and save money. Coordinated work with other local agencies generated over $5 million for the community. Because this effort was coordinated, local agencies did not compete for the same funding resources. Instead, they divided all potential funding sources, pursued funding individually, received the funds, and then used the resources to further the goals of their shared agenda.

Oakland, like other sites, has worked in partnership with local businesses to help create jobs and to provide technical assistance for those entrepreneurs building businesses in Healthy Start communities. As the religious community has become involved, local churches have begun to sponsor job skills training, community housing development, and a "member network" of volunteers offering expertise and assistance to community residents. The Healthy Start site coordinated these efforts with an emphasis on bringing major community service agencies together in a "one-stop-shopping" model co-located with WIC services, a family life resource center, and a counseling center. This coordinated approach expands access to all services, including economic development initiatives.

### *Public/private partnerships are markers of success*

The New Orleans Great Expectations Healthy Start site helped form an entrepreneurial board to assist local residents with business development. The board provides technical assistance in accounting, legal, and finance areas. The board also works with the community to ensure that members of the community support the new businesses by purchasing goods and services.



Neighborhood entrepreneurial development has proven very successful. Many small businesses, old and new, now share rental space and expenses, thereby easing the burden on all business owners. New business owners are working side-by-side with established business owners, building valuable relationships. Great Expectations has networked with local businesses that value skilled workers and has improved employment opportunities. This successful public-private partnership has helped develop the economy within the community.

The Philadelphia site also has worked to bring together public and private stakeholders, focusing on existing local businesses and human service agencies. A network of 60 partnership agencies has been established to provide programs, services, and employment opportunities to Healthy Start clients. The larger goals are to (1) encourage general hiring within the community (not limited to Healthy Start clients), (2) encourage existing businesses to grow and expand within the community, and (3) attract new businesses.

### *New services and opportunities are markers of success*

As part of New York's shared agenda with other local agencies, Healthy Start funds have been used in several ways. Community members can obtain financial assistance to take a course at a local college where they can earn a certificate and gain marketable skills. A community youth center was remodeled and programming was expanded to include nontraditional activities. A community-driven neighborhood alliance project has been started so that residents can establish their own priorities to improve their neighborhoods. Healthy Start in New York has helped target some of these funds to finance

programs for high-risk women. Using this approach, everyone is a winner—especially the community. Evaluations must reflect these stories to show the power of the Healthy Start model.

Great Expectations, the New Orleans Healthy Start site, focused its economic development efforts on improving individuals' community status through employment. With funding from Great Expectations, a community college trained 120 people to serve as project outreach workers. Of the original 120 trainees enrolled, 114 continue to work in their communities. Before participating in this program, one-third of the individuals were receiving welfare assistance, one-third were unemployed, and one-third had incomes scarcely above the federal poverty level. These outreach workers now generate $1.6 million through salaries and benefits—dollars that are reinvested in the community through the purchase of goods and services. The New Orleans site provided training to members of the community who have gained not only purchasing power, but also increased mobility in the private sector.

### *The task of economic development can seem overwhelming, but its rewards are great*

Some have wondered whether it is reasonable and realistic to make economic development a part of Healthy Start. Although the challenges are great, economic development gets at the roots of infant mortality reduction through community involvement. Economic development is fundamental to creating change in individuals' lives and improving community well-being. The task for local evaluations is to demonstrate successfully how Healthy Start efforts are fueling economic development and how economic development, community revitalization, and empowerment initiatives are making the Healthy Start goals a reality.

## CONSUMER VOICES

*Jimmie Brown, New York City Healthy Start*

Ms. Brown first came to the attention of the North Manhattan Perinatal Partnership as a consumer in the Family Redirection Program, where she received family counseling and case management services for herself and her six children. She participated in a workshop training series to become a surrogate parent to children placed in foster care and receiving special education. This program provided the inspiration and incentive for Ms. Brown to return to college to earn her degree. Today, Ms. Brown serves as secretary of the North Manhattan Perinatal Partnership's board of directors, serves as an officer of the Community Involvement Committee, and attends The College of New Rochelle—all as a result of the program provided through Healthy Start. These are her words.

"I was a teenage mom, too. I got pregnant in my last year of high school. But I graduated at the top of my class, regardless, and I also ran off and got married. Now I have six kids. I became involved with Healthy Start through one of their subcontracts, Family Redirection, because we were having family problems. There was violence in the family, so they involved me in a parenting program. This was sponsored by the New York Urban League, which is our sponsoring agency for Healthy Start in Central Harlem. The parenting program addressed children of all age levels through 21 years. It so happened that I had a child in each age level, including a six-month-old baby.

"At first, I didn't know there were programs like this. When I was first contacted and asked if I needed anything, I said no. I was visited a few times and finally I said I needed something to help me with my family. I received a letter two weeks later from Family Redirection and I tore up the letter. I wasn't going. I received the letter again, and I tore it up again. A couple of weeks later, there was a knock at my door and it was the director of Family Redirection, Ms. Jordan, and my caseworker-to-be, Ms. Caldwell. They came in and talked with me. I decided that I would go to the program, and when I went for the first time, I took all my children. They put me into a parenting program, and through this

program they sent me to the Committee on Special Education workshop to get me involved in becoming a surrogate parent for children in foster care. By going there and working with the committee, I got involved in going back to school. In fact, one of the committee members got the application for me.

"The committee told me that instead of doing volunteer work, I needed to get paid for it because I had the skills. Now I am in my third year of college, trying to get through. In the process of going back to school, I realized that my high school diploma wasn't enough to inspire my kids to keep on going. Since I have been in college, one of my sons has finished high school and has earned his associate's degree, and he is looking forward to getting his B.A. I have a 22-year-old, a 16-year-old, a 15-year-old, a 10-year-old, and a 5-year-old. I also am the grandmother of two, with another one on the way.

"Once I finished the parenting skills class, I continued to work for the Committee on Special Education while going to school. Ms. Jordan called me last year and asked me how I felt about infant mortality and I told her that something needed to be done because health is important. I didn't think that we had enough programs for all those people who needed health care while they were pregnant. She asked me if I would serve as a board member on the Northern Manhattan Perinatal Partnership and I told her I would.

"I became more involved and was able to help them with their management and government, their mission statement, and their strategy, and I served on many different committees. As I became more involved, I told more friends and neighbors so they could receive services. Even when my daughter became a teenage mom, she went to the program, and now she is doing the same thing I did. It made me realize that we really need to encourage prenatal care early. For me, even when I was pregnant with my last son, I could not be seen at the clinic until I was three months pregnant, and we know that we need to get people to go to the clinic as soon as they find out they are pregnant.

"Working with this perinatal group has helped me stay focused on what I am doing and has helped me with my children. There are so many teenage moms out there. My daughter repeated history—I got pregnant when I was 17 and so did she. I want people to realize that we need the

health care because we know there are lots of girls who have lost their babies to miscarriage without this care. I found that Healthy Start has been able to give girls the initiative to go to the clinic, get comfortable, and trust someone to help them."

71

# LINKING WITH STAKEHOLDERS: BUILDING BRIDGES TO RESOURCES

The benefits of knowing the environment and knowing the project are lost if not put to use. Understanding the environment and evaluating activities are steps on the path to sustainability, but the path must reach resources. As always, the covenant with the community forms the basis for the next steps projects must take.

*"Sustaining your project means collaboration kicks in as never before. Let me hear you say, 'I will need partners.' There are going to be public-sector partners, but, more important, you're going to need partners in the private sector. We focus too much on the initial grant instead of developing the partnerships."*

— Joseph Reid, Director of Grants Development, City of Atlanta

With the community leading the process, each project must build relationships with stakeholders who provide resources. Each community has its own stakeholders; no two networks of partners will be the same. Even within the same community, partners will change over time. Although the stories of the individual partners presented here are not relevant to every project, the strategies for building bridges to resources apply to all. These strategies must be employed continually to build and maintain partnerships that will sustain community-based initiatives.

## Capacity Building for Sustainability: Leadership, Momentum, and Results

In Healthy Start, the effort to develop support in the community is called consortia development. Today's political climate presents no opportunities for programs that do not build capacity for sustainability. Joseph Reid, Director of Grants Development for the City of Atlanta, shared his philosophy of sustainability for community-based initiatives, a philosophy based on partnerships for establishing leadership, maintaining momentum, and communicating results.

Sustainability depends on the public sector, the private sector, and the community. Community-level partnerships often do not outlive the grant—sometimes they don't live beyond the initial award. When programs are trying to get funding, they seem to know how to engage the community. Some initiatives don't appear to care about community involvement after getting the grant.

Projects need the advocacy of the community in order to touch the public and private sectors. Support won't come top-down. In Atlanta, Reid and his colleagues designed a capacity-building system, which they call "Leadership, Momentum, and Results."

*"What we're talking about here is a partnership—not a part-time partnership, but a full-time partnership."*

— Joseph Reid, Director of Grants Development, City of Atlanta

## Leadership

### *Those involved with community-based initiatives must lead the community*

Leadership is the ability to energize others around a vision for the future. Project staff and consortia members are leaders. The community sees them as leaders (whether or not they see themselves in this way). They must work to develop leadership skills because they will be "on the spot" if they have accepted the responsibility of leadership.

The project must develop the capacity of the community to participate at the grassroots level. Leaders are not born; they are "grown." Like any growth process, this takes nurturing. These leaders then become the nurturers. To accomplish this, staff must share information at the grassroots level. Initiatives need this broad participation for broad buy-in.

## Momentum

### *Sustaining momentum is sustaining the initiative*

Projects do not last if they don't keep the momentum going. In the beginning of any project, everyone is excited. But it's the momentum that keeps the money coming. Momentum is the force that moves individuals toward goals. Leadership encourages momentum by continually making specific goals and objectives of the program initiative clear to the people with whom the project works—the community.

Building capacity means developing an organization that is sustainable. At the organizational level, it means life after the project director is gone, after others are gone. At the public level, building capacity means creating community development corporations. That's what a corporation is—an invisible, intangible entity that has "perpetual life."

## Results

### *To build partnerships, initiatives must demonstrate holistic results*

Historically, human services have had difficulty thinking in terms of results. At best, they can count the number of lives sustained as a result of the program. They can say, "The infant mortality rate was X; as a result of an infusion of capital in this program, it's now Y."

In community-based human service initiatives, results are holistic, not just numbers based on the medical model. Holistic results refer to the help that everyone receives—the family, the mother, the father, the other children. Results capture early successes and measure continuous progress and impact. "Numbers served" used to suffice to keep the money coming. In the year 2000 and beyond, projects will have to show impact rather than numbers served.

Impact is not necessarily the same as successful outcomes. Impact means a noticeable change at the community level. Impact is a holistic change integrated into a variety of services—a change in the family, the neighborhood, and the community.

The ability to report results—a demonstrated change in the community—is crucial if stakeholders are to buy in to the project goals. The private sector must be committed to the project's goals in order to support it. Stakeholders must become aware of the process. They've got to help projects surround themselves with the resources needed to achieve the goals.

### *Projects must demonstrate impact, not just output and outcomes*

Impact also means robust deployment—a comprehensive approach that is integrated at all levels. Projects are covering more than infant mortality, and they're linked with other partners. The goal is for people to say, for

example. "Healthy Start is the best program. It complements Head Start." When people talk like this, the project can be confident that it will be sustained.

Demonstrating results means evaluating your program. Successful evaluations link investments to implementation with impact potential. That means the money goes into projects that work, into strategies that work, into priorities that work. That may mean streamlining the organization and making sure the money goes where it is most needed.

Leadership at the community level, momentum at the public level, and results at the private level: When you put all of this together, you've got a structure that's going to be self-sustaining over the long term.

## Building Bridges to Community Stakeholders

### Involving and Empowering the Community

*"You've got to reach down to the grassroots. Sustainability has to do with a buy-in at the local level, at the neighborhood level. And if the people you work with don't buy in, that project will not succeed. I didn't say 'may not succeed'—I said 'will not succeed.'"*

— Joseph Reid, Director of Grants Development, City of Atlanta

All of the Healthy Start sites have struggled with involving and empowering the community. In this section, four Healthy Start sites—Milwaukee, New York, Pee Dee, and Oakland—share their lessons from this difficult process.

*"When the program is done, what will it leave for the community, for us?"*

— A Healthy Start Consumer

## Milwaukee Healthy Start: Diversity and Decision Making

***Community-based initiatives can replicate elements of success***

The Milwaukee Healthy Start project is known as the Milwaukee Healthy Women and Infants Program (MHWIP). Milwaukee's Community Task Force is the vehicle for community involvement and participation. The task force consists of 125 members, 45 to 50 of whom are active. Milwaukee's Consortium is composed of the Community Task Force members (a majority), providers, and community-based organizations. The Consortium is chaired jointly by the Milwaukee Commissioner of Health and the chair of the Community Task Force. MHWIP's board of directors, which oversees the Consortium's 12 committees, is composed of 11 Community Task Force members and eight representatives of agencies and organizations.

Milwaukee Healthy Start believes the Community Task Force is successful because it:

- Demonstrates commitment to Healthy Start's goals and spreads the Healthy Start message;
- Demonstrates commitment to improving health;
- Reaches out to individuals to recruit participants; and
- Reduces barriers to members' participation by providing transportation, child care, and a meal for all meetings.

*"The task force walks the walk and talks the talk of Healthy Start."*

— Deborah Jack, Chair,
Milwaukee Community Task Force

### *To be legitimate, consortia must reflect the diversity of the community*

The Milwaukee Community Task Force is inclusive, with members representing diverse cultural and economic backgrounds. Members respect each other's diversity and accept all members nonjudgmentally. Community members who are struggling with addiction, for example, are welcomed to the task force. The group feels that because drug addiction is part of the community, these voices are important and should be heard.

### *To encourage continued involvement, consortia must meet their members' needs*

The chair of the task force, rather than relying solely on her own perceptions, encourages full participation by asking members to define their needs and desires. The chair also ensures that all participants understand the issues and that information about other meetings is shared.

Conflicts are resolved within the task force, and meetings don't end until the conflicts are resolved. This method keeps people actively participating by ensuring that their needs are being met. Other needs such as shelter and food are also tended to by the "family" of task force members. These members serve as a support system for each other, sharing in each others lives.

### *The community voice must be powerful in decision making*

The chair of the task force is responsible for ensuring that the community is involved in all levels of decision making. The community is at the table when an initiative begins, and is visible at all levels of public decision making. When the chair speaks for the group, the audience knows that she is a messenger of the community's voice.

The task force was taught that the community must take ownership and exercise control, and it has learned that lesson well. The task force is crucial to the creation of a program that differs from those that have come and gone before, a program that generates effective, ongoing change.

Milwaukee community members have struggled to maintain community ownership. They have succeeded by rallying among themselves and taking their needs to the MHWIP project director, who believes in community ownership. Community members cannot wait for someone else to give them control; the community itself must assume this authority.

## New York City Healthy Start: Lessons for Coalition Building

### *Community involvement must be born and must grow with the project*

New York City Healthy Start covers a broad area comprising three districts—Mott Haven, Central Harlem, and Brooklyn. These areas have a population of 378,000, with 136,000 women of reproductive age and 11,000 births per year.

New York City Healthy Start has emphasized community involvement in planning and implementing the program. Community involvement has been the most challenging element for the New York project to achieve and sustain. Building coalitions and community involvement is a dynamic process; the program must learn and adapt along the way.

### *Community-based initiatives can learn New York City Healthy Start's lessons:*

- Identify stakeholders and engage them at the outset. Stakeholders in the project include all who can affect or be affected by Healthy Start programs, including consumers, churches, community-based organizations, and businesses.
- Overcome obstacles. These obstacles include the territorial debates (which always exist in diverse groups), competition for limited funding, political maneuvering, stereotypes toward and within the community, and the sociopolitical context.
- Reach into the community. The New York project has reached the community through working with community-based organizations, which have built-in credibility as long-term community members. The site has also developed project area and local consortia with governance bodies.
- Identify service area strengths. New York worked to build on the community's existing assets. To have sustainable impact, the program must give technical assistance to the community regarding sustainability of its assets.
- Develop by-laws. Once the project plan has been developed and implementation has begun, by-laws are needed. Retreats are useful for developing these by-laws, which tell how to make the plan happen by defining roles and relationships and helping stakeholders to internalize their roles.

- Develop a consensus vision by bringing together all of the stakeholders. This is a dynamic and ongoing process. In the New York site, each person defined his or her vision for Healthy Start; the project then used a facilitator to help develop consensus.

New York City Healthy Start offers these tips for making progress:

- Realize that it takes more time than anticipated to develop and implement a collaborative process
- Define roles quickly
- Define community participation at the outset
- Make the extra efforts needed to involve consumers and sustain their involvement
- Build on community assets and infrastructure, using community-based organizations
- Recognize that all have a stake, and that collaboration is necessary to reach project goals
- Build adequate infrastructure to sustain the program's impact
- Build in mechanisms for continuous feedback and sustained participation
- Balance roles and encourage collective leadership
- Be aware that sustaining coalitions, community involvement, and interagency collaboration is an ongoing challenge

*"Give community organizations and leaders an opportunity to be crafters of the program."*

— Michelle Drayton-Martin, Project Director, New York City Healthy Start

## Pee Dee Healthy Start: Community Decision Making in Community Involvement Initiatives

Pee Dee Healthy Start provides services in six rural counties, with each county having a coalition of 35 voting members. Limiting the number of

members helps the project achieve a balance between providers and community; subcommittees help to broaden the membership. The six county coalitions come together to form a Regional Council, comprising the chairs and vice chairs of the coalitions. The Regional Council, which reports to the State Governing Consortium, is responsible for ensuring coordination among the six county coalitions and serves as a problem-solving body to address issues of regional significance.

Pee Dee Healthy Start's State Governing Consortium is composed of partner agencies—the Department of Health, Medicaid, United Way, the governor's office, community health centers, the medical association, the hospital association, March of Dimes, consumers, and the business community.

### *Community involvement from the beginning and at all levels creates community buy-in for project initiatives*

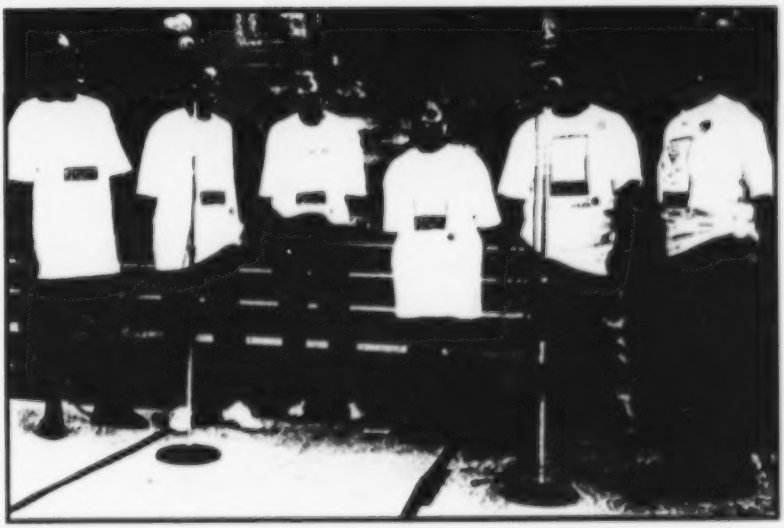
Pee Dee Healthy Start's Interfaith Initiative, one of several strategies, is a community-driven initiative that funds churches and civic organizations. Funds are awarded through a competitive request for proposal (RFP) process. This initiative has the potential to reach a broader audience through the action and empowerment of the area's churches. It relies on community-based organizations for implementation and is managed by Consortium decision making.

The application process involved the community in the entire decision-making process. First, a subcommittee of the coalition held community meetings to gain feedback on the RFP. Churches and civic organizations then submitted proposals for reducing infant mortality. After reviewing and rating the applications, the subcommittee made recommendations to the county coalition, which approved or amended the subcommittee's recommendations.

Because the community was involved at every level of decision making, the few changes made by the county coalition were accepted by the subcommittee. Community involvement at the beginning of the process led to a very enthusiastic response by churches and civic organizations. Pee Dee Healthy Start has awarded 42 contracts through this initiative in the first two years, and 15 additional contracts during the third year.

### *The community requires preparation if it is going to become involved*

Through this process, Pee Dee Healthy Start learned the importance of thorough preparation when going into the community. Simply issuing an



RFP is not enough. The project must provide information, have clear plans, and train community organizations during the proposal process. The project must then take extra steps to help funded organizations plan and implement their programs. Once the new programs are running, Healthy Start can take a step back. The technical assistance provided by Pee Dee Healthy Start includes the work of a staff member to help Interfaith Initiative projects become self-sustaining beyond Healthy Start funding.

### *When there is a history of antagonism, special training and other measures may be required to avoid fueling adversarial relationships*

Pee Dee Healthy Start incorporates several other initiatives to foster community involvement and empowerment. Healthy Start funded local alcohol and drug prevention and treatment agencies to hire women's counselors, for example. Local coalitions met with providers to review progress reports on the programs and to make recommendations regarding continuation funding and other issues. These meetings were a start, but were not as useful as Healthy Start had hoped. Healthy Start didn't consider the long-term impact on relationships between providers and the community. The providers were uncomfortable with answering directly to this group. Although the meetings were viewed by some as antagonistic, Healthy Start felt the meetings were needed to involve the community in this funded activity. In the future, Pee


BEST COPY AVAILABLE

Dee Healthy Start plans to better train the coalitions and to relay recommendations without hurting feelings.

## Oakland Healthy Start: Effective Collaboration with Community-Based Organizations

The Oakland Healthy Start project has two types of collaborative partners—those who receive direct funding from Healthy Start, and those who don't. Approximately 20 organizations receive direct funding, including health centers, hospitals, health care organizations, private corporations, and an academic institution.

The organizations that do not receive direct Healthy Start funding participate in the Collaborative. Members of this Collaborative include foundations; community-based organizations; hospitals; political leaders; universities; state, federal, and city agencies; community citizens; and private business.

### *Collaboration requires understanding the culture of each other's organizations*

In Oakland, the Healthy Start site has learned that working with other organizations can cause clashes. Each organization has its own culture and its own way of doing business. Healthy Start must understand the culture of an organization in order to be respectful and to work together effectively. Conversely, collaborating organizations must understand the Healthy Start grantee's culture, which includes bureaucracy. Organizations must learn to support each other and always remember that they are working toward a common goal.

> ***"Creatively fighting against infant mortality takes a lot of energy, yet has few visible rewards. That's why we must support each other."***
>
> — Gloria Cox Crowell, Community Liaison, Oakland Healthy Start

### *Initiatives need staff with time dedicated to coalition building*

The Oakland site has developed a community liaison position, which can be replicated in other initiatives. A community liaison must:

- Know community-based organizations, including churches;
- Know other community-wide and collaborative efforts;
- Know community leaders, gatekeepers, and opinion leaders;
- Know the principles of community organization;
- Know similar programs in the area; and
- Act as an ambassador for Healthy Start.

Oakland's community liaison improves linkages with the community, thus improving community involvement and empowerment. Much of the community liaison's role involves attending meetings to coordinate activities with other organizations and coalitions, such as the following:

- Empowerment Zones/Enterprise Communities
- Healthy Cities/Healthy Communities
- Healthy Mothers, Healthy Babies Coalition
- Community Development District Boards

For the Oakland project, these local meetings are important:

- The Oakland Healthy Start Consortium and its task forces
- Outreach Roundtable Network (provides group supervision for outreach workers)
- HIV/AIDS Coordinating Council
- Community Action Agency
- Coordination with California's statewide Healthy Start program

## Joining Voices: The Healthy Start Consumer Caucus

At the 1994 Healthy Start Grantee meeting, consumer participants came together to develop recommendations for the Healthy Start Initiative. Presented here are the discussion and resulting recommendations. In joining voices, the Healthy Start consumers provide a powerful example of community initiative, collaborative process, and consumer perspectives.

The consumer caucus was conducted as an open forum facilitated by Lillie Fox, a consumer who is now a Healthy Start consortium member. Although the caucus focused on consumers' voices, others joined, including consortia members, Healthy Start staff, and federal government staff. Many of those present who were not consumers wanted to hear the perspectives of consumers from various Healthy Start sites.

*"I hope we can share ideas since we all have the same problems, even if we approach them from different angles."*

— Lillie Fox, Pee Dee Healthy Start

***Consumers can join forces at the community level and at the national level***

Consumers stressed the importance of networking together to share lessons learned, to unite as a viable unit, and to provide feedback to the federal government about programs and outcomes. Before the caucus was called to order, the consumers compiled an address list so they could remain in contact following the meeting.

Consumers came to present the needs and concerns of their constituency, not just themselves. Often the most effective route for voicing concerns at the community level is through the project director.

*"We must remember that all consumer needs are different. Consumers must talk about their own needs as well as bringing the problems of their constituency to the surface."*

— A Healthy Start Consumer

### *Encouraging participation has many facets*

Some sites noted that consumer attendance is poor at local Healthy Start meetings. Consumers said they wanted to feel welcome at the consortia meetings; being welcomed includes making meetings accessible at convenient times. Other ways of encouraging participation involve attitudes. For example, the project must show respect for individuality and differences and must recognize the value that consumer participation brings to the project.

> *"To get participants, don't say, 'You need Healthy Start.' Instead, try saying, 'We need you.' Come sensitively, be respectful, and mean it from the heart."*
>
> — A Healthy Start Consumer

### *Commitment, caring, and respect form the basis for partnership*

Consumers and staff agree that Healthy Start works best when the staff have a personal commitment to helping others. Mothers at one site, when asked why they participated, responded: "Because you cared." Another site shows caring by taking a snapshot of the mother and baby in the hospital and putting a bow on their front door in anticipation of their return home.

Being respectful means helping consumers get what they know they need, not what staff think they need. Programs need to ask consumers what they want without analyzing whether it should be given to them.

> *"Don't ask me what I want and when I say, 'I want an apple,' give me an orange. You have to try to find an apple, even if all you have is an orange."*
>
> — A Healthy Start Consumer

### *True consumer involvement is necessary to reach the Initiative's goals*

Some consumers expressed concern about their role in Healthy Start. One consumer said, "We are tired of being surveyed. If the consumer's role is eliminated once the development piece is completed, then I do not want to be bothered."

Consumers emphasize the importance of Healthy Start taking a "bottom-up" community-based approach to reducing infant mortality. This means taking the time to explain to the community. Training must be ongoing so that workers remain in touch with the community. Project staff should be involved with the community and consider themselves members of the community.

> *"Let those close to the problem be involved. Local residents know exactly what they need. The project director, whether she agrees with the consumers or not, must have contact with the community. Healthy Start staff need to view the community as their home."*
>
> — A Healthy Start Consumer

### *Consumers' volunteer service should be valued*

Many Healthy Start consumers volunteer as resource mothers, members of the community who volunteer as mentors to mothers-to-be and mothers in need. This is a serious (sometimes dangerous) responsibility that often challenges volunteers to be nonjudgmental and accepting of others' choices.

Consumers emphasized that all consumer input should be accepted and valued. Adolescents, for example, provide valuable input, particularly for reaching out and working with young women. Sites do not always value input from these young women; sometimes even the consumer groups discount their views.

*"As local residents, we have a responsibility to set an example by remaining in our communities. Even if we educate ourselves, we can return to our communities. But even if we don't have a high school or college education, it does not matter. This program is about us. We are all capable of helping our children if it comes from the heart."*

— A Healthy Start Consumer

Contributing to Healthy Start and other community-based initiatives does not require or preclude formal education. Consumers emphasized that local residents need to take responsibility for the community, no matter what their educational background.

***To exercise power, consumers must join together***

*"We need to love one another from heart to heart and breath to breath."*

— A Healthy Start Consumer

The consumer caucus demonstrated the bond that Healthy Start consumers feel with their communities and with each other. Those who had never met before found their connectedness by sharing common experiences and common goals. The spirit of joining forces bonded participants in much the same way as local consortia can bond communities. Joining together means tolerating and respecting differences and renouncing divisiveness.

*"We must forgive each other since we all make mistakes. Not all consumers agree. We need to learn from sharing our points of view. What is right for one person is not necessarily right for another. But we must continue to embrace each other because what affects me affects you."*

— A Healthy Start Consumer

## Consumer Caucus Recommendations

Following is a list of recommendations by participants in the consumer caucus:

1. Include consumers on all Healthy Start committees, especially the grantee meeting planning committee.
2. Restructure the grantee meeting next year to include workshops for consumers to attend.
3. Make more resources available to bring consumers to the next conference.
4. Conduct on-site training for consumers.
5. Eliminate segregation between consumers and staff, particularly in meetings.
6. Include consumers in the decision-making process/collaboration with site managers.
7. Encourage consumers to seek technical assistance elsewhere if "shut out" from site managers.
8. Change the term consumers to consumers/participants.
9. Allow consumers to monitor outcomes by talking with participants.
10. Involve, at the national level, a consumer participant from each site.
11. Provide the group with a directory of consumers at other sites so consumers can organize a consumer caucus across sites.

12. Develop a consumer lobbying group at all levels to support and protect consumer concerns in Healthy Start.
13. Provide resources for consumer technical assistance and consumer lobbying groups.
14. Ensure the presence of more consumers/participants than providers on the board (e.g., 11 consumers, 8 providers) so that it will be consumer-driven.

*"We need to respect our differences and respect each other as human beings, not just as consumers. We need to learn to work together, since it is our babies who are dying! We are one entity, one family."*

— A Healthy Start Consumer

## Building Bridges to Private Sector Stakeholders

### Economic Development through Public Support

Economic development can harness the power lying dormant in communities to bring about political and economic growth. However, this task requires resources. Public resources can be used to develop businesses, job opportunities, educational opportunities, and other economic components.

### Housing and Urban Development Initiatives

#### *Economic development initiatives must take a holistic approach*

The U.S. Department of Housing and Urban Development (HUD) supports sustained community economic growth through comprehensive approaches. Economic development means more than creating jobs or credit unions. Jobs,

education, and transportation are interrelated factors. Similarly, communities are interrelated with cities, states, and the national and international communities.

This comprehensive look at needs is crucial to improving the health and well-being in any community. Many communities that have used strategic planning to launch new initiatives tend to focus on services for young people, who are the future of the community.

A holistic approach is not always supported by government funders. Projects are often forced into categories, and must therefore focus narrowly. Applications approved by HUD give preference to programs that enhance partnerships and program linkages.

*"The government structure must change to allow for collaboration among agencies to create sustainability."*

— Roy Priest, Director, Office of Economic Development, HUD

***HUD makes funds available for community economic development.***

The following programs are available to support creation of community systems.

- The Family Investment Center is a program that helps those living in public housing to get resources. Healthy Start sites could become family investment centers.
- Through the Department of Labor and the Department of Education, the Youth Fair Chance program provides training and jobs to residents in low-income housing. The Youthville program works to improve education, leadership, and skill development in construction areas.
- Another HUD program trains residents to inspect levels of lead in paint. These residents receive entrepreneurial opportunities to become inspectors, while helping to prevent lead poisoning in children.
- The Urban Parks and Recreation Recovery program provides resources to reclaim urban spaces by converting them into parks and recreation areas for children.
- The Department of Justice sponsors a similar program, Weed and Seed.

HUD distributed an estimated $1 million in the January 1995 funding phase. HUD is in the process of developing an on-line resource network to give the public access to information about funding and other resources available through HUD, the Department of Health and Human Services, and other government agencies.

*"Healthy Start sites can't stand alone. They must join forces and build partnerships."*

— Roy Priest, Director, Office of Economic Development, HUD

## Department of Health and Human Services, Administration for Children and Families, Office of Community Service Initiatives

The Office of Community Service (OCS) manages the Administration for Children and Families Block Grants to the states. The OCS Discretionary Division is designed to help people become self-sufficient through programs that address homelessness, employment (creation of jobs), adolescent pregnancy prevention, and the needs of the elderly.

### *Community-based initiatives can use OCS funding to develop private economic resources*

The Office of Community Service sponsors the Job Opportunities for Low Income Individuals (JOLI) Program, which funds three-year demonstration projects. The purpose of the program is to demonstrate and evaluate ways of creating new employment and business opportunities through provision of technical and financial assistance to private employers in the community. Nonprofit and community development corporations are eligible for this program. It is possible for another type of agency to become partners with a community development corporation and to gain access to these resources. Grant awards are fully funded for 36 months, with the maximum amount granted under this program totaling $500,000 for the three-year period. To be eligible, projects must have a comprehensive evaluation component.

BEST COPY AVAILABLE

JOLI funds 10 programs per year. Recently, this organization funded a frog farming project in Hawaii. In New York, JOLI funded a bakery that contracted with Ben and Jerry's to create a new cookie. Twenty-four homeless persons have been employed by this project. Cookie sales are picking up, and workers are learning marketable job skills.

The OCS is in its fifth funding cycle of support for these innovative economic development initiatives. Using these resources, communities can develop new businesses leading to jobs, income, and, ultimately, sustainable funding.

## Chicago Healthy Start's Economic Development Component

*"Economic development needs to become a guiding principle when designing all aspects of a program."*

— Deborah Francis, Project Area Coordinator, Chicago Healthy Start, Illinois Department of Public Health

### *Initiatives can successfully link program components with economic development*

Chicago's Healthy Start site has enlisted private and public funds to implement its program. One example is Chicago's breastfeeding promotion program. To address the lack of breastfeeding educators and training programs, the site created a partnership with WIC to train breastfeeding educators. Staff from WIC provided transportation and culturally sensitive breastfeeding training and childbirth preparation to train Healthy Start mothers as educators. Twenty-two women have completed the breastfeeding training program and are now working full time or in schools as counselors. Several women were hired by the WIC program to conduct breastfeeding training in the community.

Chicago Healthy Start used a similar economic development approach to solve another problem in the community: Healthy Start mothers wanted to use WIC coupons for items other than formula and baby food, but were

unable to do so. At the time, Catholic Food Charities managed stores where food that could be purchased with WIC coupons was available. Separate stores have been established where all items can be purchased with WIC coupons. Residents at local substance abuse treatment centers and homeless shelters have been trained to become clerks, managers, and administrators at these food stores. Eventually, these employees can make the transition into jobs at privately owned stores.

Originally, there were three stores; now there are eight. The site has initiated other employment opportunities through training residents as data collectors and as lead abatement specialists. These initiatives prove that it is possible to make preexisting programs a part of an economic development plan to raise money, serve the community, and create employment opportunities.

## Leveraging Private Resources

As a federal initiative, Healthy Start relies on public resources. However, the Healthy Start sites, like other community-based initiatives, can leverage resources from the private sector to continue their programs and to support new components. Foundations and other private funders offer fresh opportunities, and, often, more flexible funding. Many foundations' priorities match those of community-based programs. United Way, March of Dimes, and the W. K. Kellogg Foundation, for example, all give priority to community- and volunteer-driven initiatives. With information about compatible foundations, Healthy Start and other similar programs can forge relationships that will support their work in the future.

Example of success with private resources include the Boarder Baby Project and Mary's Center, both in Washington, DC. By building strong programs, public awareness, and private relationships, these projects have secured a diverse funding base for comprehensive programs. Combining public funds with private donations, foundation grants, and corporate grants, these projects have pulled together resources to support their work.

*"Information is power."*

— Patricia Pasqual, The Foundation Center

## The Foundation Center

The Foundation Center, an independent, national nonprofit organization established in 1956 by a number of foundations, provides information on foundation and corporate philanthropy and nonprofit management. The five field offices (Atlanta, Cleveland, New York, San Francisco, and Washington, DC) have free libraries that are open to the public. The offices also offer training in proposal writing and grant research, and sponsor "Meet the Grantmakers" events.

The Foundation Center belongs to a nationwide network of cooperative collections, providing information on resources and training. Professionals can call toll-free (1-800-424-9836) to learn how to access this information.

The Foundation Center has over 100 publications and several databases; a catalog of publications is available. Two of the databases are available through Dialog: the Foundation Directory and the Foundation Grants Index.

### *Obtaining private funds is competitive*

The Foundation Center collects and disseminates information on foundation giving. In 1993, $126 billion was donated to charities; 11 percent of these funds came from foundations and corporations.

**Privately Funded Grants, 1992**

*(top three categories)*

| Subject | Funds | Percentage* |
|---|---|---|
| Education | $1,346,910,000 | 25.4 |
| Health | $ 943,836,000 | 17.8 |
| Human Services | $ 847,256,000 | 16.0 |

**Percentages do not total 100 percent.*

Within the health category, grants were distributed as follows:

**Privately Funded Grants in Health, 1992**

*(top four health categories)*

| Health Category | Percentage* |
|---|---|
| Hospitals and Medical Care | 39.0 |
| Medical Research | 24.0 |
| Reproductive Health | 6.0 |
| Public Health | 5.0 |

**Percentages do not total 100 percent.*

Given the number of nonprofit organizations (500,000–600,000), competition is tough. The average budget for a nonprofit organization claims 31 percent of its funding from government, 51 percent from fees, and 18 percent from private giving.

### *There are differences between public and private funding*

While public funding provides larger awards, private foundations require shorter proposals. Public funding normally covers indirect costs, while private funding generally is more flexible. Less red tape is involved in changing project budgets with private funding. Private funding is less tied up in politics, but is also less accessible. For example, only 25 percent of foundations have a staff, so some foundations can be difficult to reach.

### *Projects can take steps to successfully obtain private funding*

Research is the key to success. This research has three basic elements:

- Selecting the right person to research opportunities—this person must be creative in order to find a match for the organization.
- Being organized—set up donor files and take notes on index cards or on computer.
- Allowing enough time (9–12 months)—most foundations have board meetings quarterly.

*"Foundation research is an art, not a science."*

— Patricia Pasqual, The Foundation Center

*What to Ask*

The organization must match the foundation's mission, especially in the following areas:

- Broad subject areas
- Geographic areas of interest

- Type of organization funded
- Types of support needed by the organization
- Range (size) of grants available

*How to Research*

In seeking private funding, organizations are most successful if they start locally. The following documents are useful in conducting research:

- Directories
- Donor publications
- Tax returns and grant lists
- News clippings for up-to-date information
- Phone calls for updates

*Where to Look*

Information on foundations is available in a number of resources.

- State and local directories
- General directories such as the Foundation Directory
- Subject directories such as the National Guide to Funding in Health, Fundraiser's Guide to Human Services Funding
- Directories of population groups such as the National Guide to Funding for Children, Youth, and Families; and the National Guide to Funding for Women and Girls

### *The Grantwriter's Plea*

*Grant me the courage to write and submit a grant, the serenity to deal with the denial of the grant, the wisdom to know whether to revise and resubmit the grant.*
*Please, grant me a grant!*

—Soraya Coley

### *Tough times call for more inclusive practices*

The Foundation Center offers the following tips for tough times:

- Think broadly—remember to think about the funding mix (in which foundations often are a small part)
- Involve everyone—include clients and organize events
- Work smarter—target funding sources carefully
- Build relationships—follow up on all connections

## United Way of America

### *To become a partner with United Way, initiatives must know their local agency*

United Way comprises 2,200 local agencies, which are described as "fiercely autonomous." They respond to their own communities' needs. Nationally, United Way raises $3.1 billion, 91 percent of which is raised in the workplace through corporate and employee contributions. These funds are distributed to a variety of programs. Some major categories include:

- Health (22.2 percent)
- Families and children (19.8 percent)
- Federal youth programs (16.8 percent)

This funding is allocated by panels on topic areas (e.g., health, family services, emergency relief) and is distributed by need. To be competitive for funding, programs must know how their local United Way agency operates and must meet the following criteria:

- Qualify as a 501c(3) organization
- Have a governing board of directors
- Have an affirmative action program
- Provide a nonduplicative service

There are three ways to obtain funding from United Way.

- The standard allocation process
- Field of service designations (donors specify categories or agencies when they contribute)
- Special Venture Demonstration Grants, which provide seed money

Following are some questions to consider when applying for United Way funding:

- Should you "go it alone," or collaborate with another agency?
- What are the local United Way's priorities?
- Will your proposal address narrow goals such as infant mortality, or broader goals such as preventive health?

### *Projects applying for United Way support should address the United Way's priorities*

These subjects reflect donors' preferences, as manifested in United Way's funding priorities:

- Prevention
- Public-private collaboration, creating a "conspiracy of caring"
- Diversity (culturally competent, grassroots outreach with the community)
- Cost-effectiveness (donors want a return on their investment—they give money in order to make a difference)
- Results-oriented programs
- Comprehensiveness (with special emphasis on family-based initiatives)
- Volunteer-driven initiatives (in governance and in program design)
- Relevance to education

### *To secure the future, initiatives should build relationships now*

- Get to know the local processes now, and keep informed. Eighty-eight percent of United Way agencies have retooled their processes, and 80 percent will be retooling again soon. Programs should try to be a part of this restructuring process. Start a dialogue with United Way and business leaders, and ensure that the agency's leaders know the benefits of the program.
- Develop local relationships with United Way. The project should run an employee campaign, a volunteer program, and/or be a part of United Way's needs assessment process.
- Work with community foundations that have flexible funding (e.g., Kiwanis, March of Dimes, and Gifts in Kind America).

United Way has not viewed Healthy Start sites as potential grantees. To change this perspective, Healthy Start and other similar initiatives should connect with local United Way agencies, highlighting Healthy Start's commitment to new decision-making processes as a strength. By following these guidelines, community-based projects can begin to forge relationships that will sustain them in the future.

## W. K. Kellogg Foundation

In 1930, W. K. Kellogg, inventor of the corn flaking process, established the W. K. Kellogg Foundation with $40 million. The foundation has three areas of concentration—health, agriculture, and youth. Programs that integrate creative ways of addressing all three categories are most successful in obtaining funding.

The W. K. Kellogg Foundation believes there are three essential elements to successful private fundraising:

- Know your foundation
- Be community based
- Be creative

Programs are encouraged not to rely on foundations or any one source for all ongoing funding.

### *Building relationships depends on knowing the foundation's philosophy*

In building a relationship with the W. K. Kellogg Foundation (or any foundation), it is important to know the philosophy—the principles, values, and interests of the founders. Kellogg's philosophy is grounded in community-based problem solving, with the following emphases:

- Community self-determination
- Application of existing knowledge (not conducting research)
- Comprehensive solutions—approaches that fit into the broader scheme
- Reforms in systems of care (a shift to strategic initiatives with public policy and systems impact)
- Impact outcomes (focusing on the bottom line)

***Kellogg's Families for Kids Initiative provides insight into the foundation's philosophy and priorities***

This Kellogg initiative sponsors 18 child welfare projects. The goal is to change the child welfare system so that foster children are adopted more frequently and more quickly. In 1991, approximately $36 million was allocated to these projects. Adoption proposals, for example, often focused on finding homes for a specific number of foster children; however, this solution doesn't affect the number of children entering foster care. Thus, system reform was needed. The intended outcomes of this initiative are:

- Family support systems;
- Assessment systems;
- A one-to-one approach (one team working with one family);
- One foster home per child; and
- A permanent home within 12 months.

Healthy Start and other community-based initiatives are at the "front end" of the child welfare system, while his initiative focuses on the "back end." Projects should think creatively about involvement in this and other foundation initiatives.

## Healthy Start Projects Sponsored by March of Dimes: Public/Private Partnership

The March of Dimes mission is to improve the health of babies by preventing congenital disabilities and infant mortality. Their Campaign for Healthier Babies involves four components:

- Facilitating access to community services at all levels
- Conducting advocacy
- Sponsoring research on reducing congenital disabilities
- Educating and informing the public about prenatal health

### *March of Dimes became a partner with the federal government to expand the Healthy Start Initiative*

Initially, 15 sites were approved and funded by the federal government for the Healthy Start Initiative. Six sites were approved but not funded. The March of Dimes donated $100,000 to these "unfunded" sites over a two-year period. In addition to these donations, the March of Dimes worked with sites to obtain space and materials. Although two sites were discontinued, the March of Dimes continues to sponsor the remaining four: Savannah, Georgia; the Delta region in Mississippi; Dallas, Texas; and Milwaukee, Wisconsin.

### *Building on March of Dimes funding, Healthy Start sites have brought in other private funds*

At the Milwaukee Healthy Start site, staff leveraged $22,000 dollars from the Helen Bader Foundation and the City of Milwaukee Health Department. Founded in 1992, the Milwaukee Healthy Women and Infants Program is developing a comprehensive, culturally competent, and community-driven perinatal and infant health care delivery system.

In Dallas, the Dallas County Hospital District/Community Primary Care Program teamed up with the March of Dimes in 1991 to form a consortium of agency service providers, consumers, and community representatives in order to remove barriers to prepregnancy care in low-income areas of west, central, and south Dallas. Staff obtained additional funding from Crystal Charities and the Cigna Corporation.

### *Projects can build coalitions to develop resources*

Dallas Healthy Start suggests establishing a resource development committee to generate fundraising ideas. The project offered the following steps to establishing such a committee:

- Recruit 12 people from a variety of backgrounds who have responsible roles in the community, including consumers.
- Bring these 12 people together to form the resource development committee, which submits proposals to corporations for funding.
- Include members who may be connected to community organizations, capitalize on contacts with nonprofit members, and network through them.
- Attend all meetings in the community and talk about Healthy Start.
- Remember to listen to the concerns of the community.
- Once the program is implemented, conduct focus groups with those who used the services—consumers often address issues of which the program staff are unaware.
- Be prepared to act on feedback from these focus groups in order to improve the quality of the program.

### *To market the project, staff must understand what information the funder needs*

Before applying for grants in the community, the Dallas Healthy Start site collected information about the area it hoped to serve. Dallas Healthy Start recommends that, when approaching organizations for funding, the project:

- Have a mission statement that is readily understood;
- Bring consumers to the meeting;
- Bring some simple statistics to the meeting;
- Provide an estimated budget with a solid evaluation plan; and
- Emphasize the visibility that the funder would receive.

### *Private funding can offer flexibility to make capital investments*

The Dallas site has leveraged private resources for equipment crucial to its innovative approaches. For example, a Winnebago equipped with examining rooms and medical equipment was supported by $200,000 from Crystal

Charities. The Dallas site also has two "mom mobiles," donated by the Cigna Corporation, to transport mothers and infants to medical appointments.

### *Private funding can provide flexibility to address community priorities through innovative strategies*

The Mississippi Primary Health Care Association is working with the state Health Department and the March of Dimes chapter to develop an initiative to combat high teenage pregnancy rates, infant mortality, and low birthweight problems in three economically depressed rural counties in the Mississippi Delta.

One county had a family focus, recruiting families in the community to "adopt" at-risk young women ages 14–16 years. Families offered these teens guidance, resources, or a place to stay. Another county developed a male mentoring program for boys ages 12–14 years. The third county worked with Head Start, using resource mothers to identify young women at risk and to recruit them for prenatal services. All of this was accomplished with a small amount of money that brought advocates together to make a difference in the community.

In the Savannah site, staff developed a newsletter to increase public awareness of infant mortality issues. Staff also worked to involve men in prenatal infant care. Savannah's project director organized a legislative breakfast, with extensive media coverage, to gather community and political leaders to hear the project's concerns. Building community-wide change was an important part of this effort, which led to establishing a men's clinic where men could see nurse practitioners and health educators. The slogan "Men have babies, too" was posted on local billboards, along with the hotline number. The site has also developed a working relationship with the Alpha Phi Alpha fraternity. "Project Alpha" became a mentoring program, connecting young men to successful working men in the community.

## The Boarder Baby Project: Public Awareness and Relationship Building

The Boarder Baby Project in Washington, DC, was established by Patty and Lynne Gartenhaus in 1990. At that time, infants were being abandoned in hospitals by their poverty-stricken and drug-addicted parents, thus creating a "boarder baby crisis." Realizing the desperate need to remove infants from the hospital setting, the project opened "The Little Blue House," a warm, homelike environment for boarder babies.

***Private donations are bolstered by in-kind contributions and community volunteers***

In August 1990, the Federal Home Loan Mortgage Corporation (Freddie Mac) donated to the project a single-family dwelling requiring extensive renovation. Galvanized by the plight of the boarder babies, the community offered labor, supplies, financial support, volunteers, pro bono services, and media support. Community efforts saved the project 50 percent of renovation costs. In fall 1991, The Little Blue House opened its doors, welcoming four boarder babies into its refurbished facility. After a successful appeal to the Board of Zoning, the capacity of the home was increased to accommodate six babies. Staff work in tandem with the Department of Human Services to secure permanent homes for each of the babies. The Little Blue House operates a small, intimate, and well-managed program that can serve as a model for private initiatives across the nation.

***Publicity can be the key to private fundraising***

The Boarder Baby Project receives no federal funding; it is supported solely by contributions from private corporations. The project has "gotten its foot in the door" though publicity. Special events in the community, such as concerts, banquets, or walk-a-thons, have been very successful.

To increase public awareness, the project passes out fliers or sends direct mailings. In 1994, the Boarder Baby Project sponsored a concert featuring LeBarge and Babyface. The concert was advertised on local radio stations, and this sold-out event was a huge success. To raise additional money, the project

*"Marketing and networking are important ways of securing funding in the private sector. Highlight one special aspect of your program. Your project must be innovative and stand out because private-sector funding is very competitive."*

— Patty Gartenhaus, The Boarder Baby Project, Co-founder, The Little Blue House

recently planned a casino night on a riverboat, advertising the event through special brochures.

Staff have developed relationships with radio personalities in order to air public service announcements on local radio stations. Developing this type of relationship may require project staff to write and call radio personnel to inform them of the project's work. To sustain these relationships, project staff should acknowledge the publicity by letting the radio stations know that these messages have generated a positive response in the community.

The Boarder Baby Project also videotaped a television news broadcast about the project and sends this videotape to private corporations. Projects with high visibility find it easier to garner support from corporations, since companies want their names advertised as much as possible.

### *Networking and publicity should be strategic*

The Boarder Baby Project stresses the importance of planning networking strategies in advance. Projects should start with corporations that endorse the program, then branch out to other companies. Private organizations often enjoy seeing the site and meeting the people involved. The Little Blue House sponsors a breakfast, inviting the principals of one organization and asking them to invite colleagues from other corporations. Through this type of invitation, the chief executive officers and vice presidents of these organizations can see the premises (and they usually "fall in love" with the babies).

When meeting with potential donors, staff should be prepared to ask for what the project needs. There is no need to wait for funders to approach your project. The project provides these tips for capturing interest:

- Give potential funders videotapes, newspaper articles, and brochures about the project.
- Ask foundations for products or services first, then ask for seed money.
- Offer incentives to corporations—telling them, for example, "If you pledge $500, you will get an exhibit table at our event; if you pledge $1,000 your name will appear on a banner."
- Offer special benefits (such as tickets to special events) to organizations that donate money.

*"If we want private organizations to invest in us, we must invest in them."*

— Patty Gartenhaus, The Boarder Baby Project, Co-founder, The Little Blue House

***Ongoing relationships are the key to ongoing funding***

Once a corporation agrees to contribute to the project, the Initiative must keep the relationship alive and share information with it throughout the year. Following are some tips for achieving this relationship:

- Do not go to the funder just as the grant period is ending.
- Educate funders about your project.
- Provide them with scientifically supported results in a clear way.
- Talk in normal language, calling clients "moms," and infants "babies."
- Realize that the evaluation component is very important—donors want to know what they have gotten in return for their investment.

## Mary's Center: Building Sustainable Programs

***Other community-based initiatives can serve as models for successful sustainability***

In preparing for the future, Healthy Start and similar initiatives have strong models. Community-based initiatives that have come before continue to survive and thrive. The Boarder Baby Project is one example. Another is Mary's Center, a nonprofit center providing maternal and child health care services to low-income, uninsured pregnant women and to children in Washington, DC. At the 1994 Healthy Start Grantees meeting, Mary's Center taught its lessons for sustainability.

Mary's Center was founded six years ago with core funding from the District of Columbia government to address the need for more accessible and culturally sensitive maternal and pediatric services in the Latino community. The Center provides diverse services, including midwifery-based prenatal care and hospital deliveries, home visiting to each new mother and child within 48 hours of delivery, intensive home visiting for high-risk families, postpartum

care, family planning, preventive health education classes, social services, case management, parent training, and adolescent programs.

Mary's Center finances a budget of $1.2 million, with very little funding from the federal government. The largest sources of revenue include foundation grants (31 percent), the D.C. Office of Latino Affairs (28 percent), patient revenues (17 percent), and the U.S. Department of Health and Human Services (14 percent). The center spends 91 percent of these revenues on program costs and only 9 percent on administrative costs.

Mary's Center has been self-sustaining because of several factors. First, the staff have been able to identify and quantify the need in the community, in order to justify more funding. Second, Mary's Center gradually has built strong programs—programs that staff believe in, that reflect the mission of the center, and that have been proven to work. To date, the Center's midwives have delivered 1,200 babies, with a 3 percent low birthweight rate, no infant deaths, and a 95 percent immunization rate. Finally, Mary's Center has become known for its teamwork and commitment throughout the funding world.

### *To survive and thrive, initiatives must be committed to effective programs*

Organizations must unite in purpose to sustain the valuable programs and services that are rebuilding communities and individuals' lives. Recommendations from the Mary's Center experience include:

- Resist pressure to dilute the mission. Mary's Center has maintained its focus on women and children, despite pressures to become a community family practice clinic. Rather than adding new programs, the Center has concentrated on improving existing services. Staff are continually assessing clients' needs and developing services based on these needs assessments. Deviating too far from the mission can result in dissatisfied clients and decreased funding.
- Solidify existing programs before adding new components. Mary's Center has been successful partly because it has evolved slowly and carefully. Mary's Center added new programs incrementally, not at the expense of the core prenatal and pediatric services. Adding incrementally is important to sustainability because the organization has time to successfully manage programs, resulting in better accountability to funding sources. This translates into a greater likelihood of future funding. Starting too many programs at once can result in failure to sustain them all, both operationally and fiscally.

- Recruit committed, long-term staff who work as team players. Staff are one of the most important factors in sustaining Mary's Center. From the receptionist to the pediatrician, each staff member has an equal voice and equal value. Like any organization, Mary's Center experiences personality clashes and conflicts, but staff have remarkable camaraderie (evidenced by the low turnover rate). A consistent staff of people who feel good about the work they are doing, about their coworkers, and about clients has direct impact on sustainability by keeping clients and funders engaged in the sense of purpose and teamwork.
- Involve staff in all aspects of program development. The success of a new program at Mary's Center has hinged greatly on whether it has "won the hearts" of the staff. Staff were not always involved in the decision-making process, but staff now decide as a group what programs are needed and how they should be designed.
- Provide high-quality services that treat clients with dignity, respect, compassion, and equality. Mary's Center has never had to advertise;

word-of-mouth and community networking have kept clients streaming in voluntarily. Even though Mary's Center charges for services, people come because they are treated with dignity, respect, compassion, and equality. This has sustained the client base and the reputation of Mary's Center in the community.

***To survive and thrive, initiatives must capitalize on the changing environment***

- Advocate for timely reimbursement from Medicaid. This keeps money in the system and allows health care delivery to run more efficiently.
- Advocate for nonphysician practitioners to participate as primary care providers under Medicaid managed care. States may save money by allowing these practitioners to serve as providers, especially to low-risk patients.
- Re-examine the quality of patient care to low-income, medically underserved populations. As observed at Mary's Center, if people are treated with dignity and respect, they will use the services.

***To survive and thrive, initiatives must build bridges to resources***

*"For every dollar the District of Columbia has invested in Mary's Center, we have been able to raise an additional three dollars from the private sector and federal government."*

— Michelle Lecks, Program/Development Manager, Mary's Center

- Build effective public and private partnerships. It is pointless for one agency to provide all needed services. Though it may be difficult to give up particular services, collaboration stretches resources and provides better service to the community. Also, funding sources reward

collaborative programs with more funding. Mary's Center has developed linkages with more than 25 public and private community-based agencies. This has stretched its budget to ensure better continuity of care for clients.

- Educate funders about your community. Public health centers need to be straightforward about the needs of their communities, even if it means bringing up controversial subject matter. Staff members and clients need to be spokespersons for the community and its needs. Mary's Center, for example, is honest with funders about the fact that it serves a largely undocumented population.
- Encourage states to lend a hand. It is in the state's best interest to become partners with independent nonprofit clinics that can broaden the impact of the public health system and raise money from sources that are not accessible to states.
- Provide training opportunities for graduate students. With this experience, students are more likely to return to community work or bring a holistic perspective to their work in other areas.
- Evolve with the community served. Agencies and organizations cannot get locked into serving a specific population or refuse to provide a service that is needed in the community. It is important that these challenges be looked upon as opportunities for growth and change.

## Building Healthy Start Networks

The 1994 Healthy Start Grantees meeting was part of an ongoing effort to help sites learn from each other to support the success of the entire Initiative. In addition to annual grantee meetings, other channels have been developed for building this network. Building links with each other has become a critical step on the path to permanence.

As part of this process, the Division of Healthy Start at the Maternal and Child Health Bureau has been investigating strategies for increasing grantees' communication through electronic media. After looking at a number of systems to promote electronic communication in conjunction with the MCH-Link Project at the Institute for Child Health Policy, the Division of Healthy Start has begun testing CDC-Wonder, a free and universally accessible means of electronic communication available to all in the health field. Services provided include electronic mail (e-mail), bulletin boards, and discussion groups.

### *Electronic communications build networks and access information*

Recently, The Wall Street Journal reported that only 20 percent of available health information is being used. Electronic communications can help Healthy Start and similar initiatives share with each other and with the world. Electronic communication has advantages and disadvantages. It is a tool to use in conjunction with other communication methods such as phone, fax, and mail. Electronic communication should be considered a way to break down barriers and find out what works in this new technology. In deciding whether (or how) to use electronic communication, consider the following:

- Individual differences in comfort level with technology
- The perceived usefulness of the method
- What peers and partners will do
- The boss's perceptions of usefulness
- Technical barriers

E-mail tends to "flatten" organizations. Organizational communication is typically vertical, with those at the "bottom" having little access to those at the "top." E-mail systems give all equal access to the top. They also help get information to and from experts.

The Maternal and Child Health Bureau has devoted funding and staff time to this effort, signifying a commitment to electronic communication. It is hoped that this initial investment will bring projects the resources to sustain Healthy Start well into the future.

## CONSUMER VOICES

*Tameka Coleman, Washington, DC, Healthy Start*

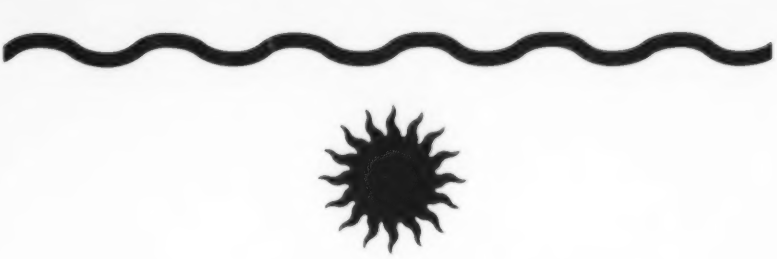
Tameka Coleman is a native Washingtonian. Seventeen years old, she is one of four children. Tameka and her family live in Ward 7 in the District of Columbia, where she is a senior at Eastern High School. Tameka has participated in the Washington, DC, Healthy Start project since early 1994. The proud mother of a happy, healthy four-month-old son, Tameka states that the Healthy Start program has helped her adjust to motherhood. These are her words.

"Good morning. I learned about Healthy Start from a counselor at my school. I was contacted by my resource parent, Veronica Brown. From then on, Ms Brown and a nurse came to my house and made sure I got to my prenatal appointments every two weeks. I started with the Healthy Start program in April 1994. That was during my last three months of pregnancy. Through Healthy Start, I was introduced to a program at my school with classes on family planning, parenting skills, what to expect during labor and delivery, and things like that. During my pregnancy, I was supported by my family, my community, and my church. I wasn't looked down on—they pressed me to keep on going.

"I was pregnant during the entire year of my 11th grade, but I went to school every day and maintained a 3.7 grade point average. Upon graduation, I plan to attend college and start a nursing career. My being pregnant really made me want to help others. I would recommend Healthy Start for any pregnant teenager, and for any parent. Healthy Start helped me right from the beginning. After my baby was born, they would come in once a week and make sure my baby was healthy, make sure he was growing, make sure his shots were up to date, and that I was healthy and getting to all of my appointments. Healthy Start introduced me to WIC and Medicaid.

"I live on a small street and my community is like a family. After the baby was born, everyone came over to see him. They really supported me during my pregnancy and afterward. Being a teenage parent is hard, but it could be harder without the help that I get from my family.

community, and Healthy Start. It's almost as if my baby is everyone's baby on my street. Neighbors come over and sit with him from time to time while I do my homework. He is the only boy in the house, and the neighbors assume that he is the boss so they call him 'the bossman.' Healthy Start has really helped me a lot through my pregnancy, and could help anyone through pregnancy."



# CONCLUSION: SUSTAINING HEALTHY START PROJECTS

### *Healthy Start Consortia have power to change the environment*

The community and its Consortium are Healthy Start's greatest allies. Community-based initiatives can educate their Consortium concerning the political process and teach the community its considerable power in the political process. The Boston Healthy Start Consortium, for example, has buoyed its political power by applying for 501c(3) status and building relationships with foundations in order to become self-sustaining. To use this power, Healthy Start Consortia must be educated concerning the "big picture."

### *Healthy Start Consortia are critical to building partnerships*

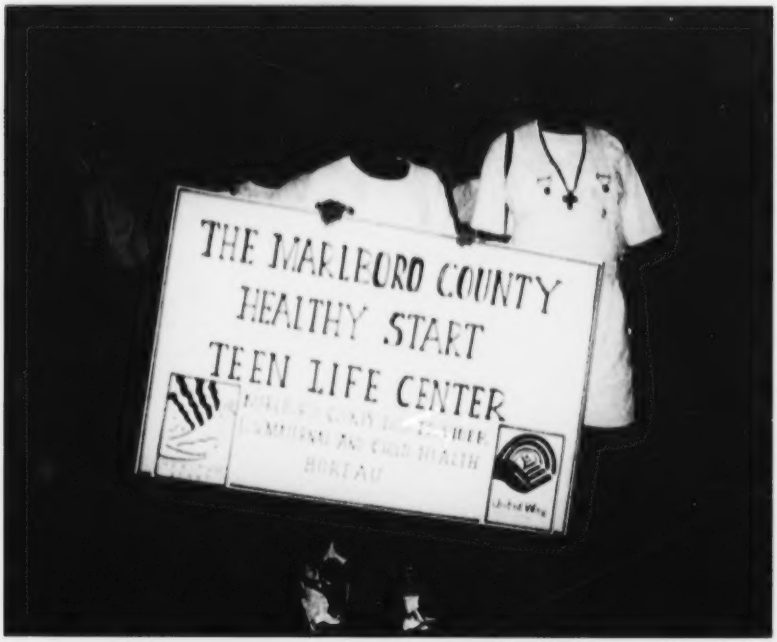
Community leaders in the Healthy Start Consortia have the knowledge to lead the Consortia and the consumers in making Healthy Start a household name. Consortia need to be educated concerning other community programs serving children and families to form partnerships for sustainability. Healthy Start staff need to work with the Consortia to develop plans of action. The doors of Healthy Start need to be open to important leaders in both public and private sectors. People from diverse areas of interest and professional backgrounds need to become part of the Healthy Start process.

Healthy Start sites need to continue to demonstrate the value and impact of their services and to speak out to consumers and the community to tell the Healthy Start story. This is especially important for sustaining less traditional services, such as breastfeeding support groups, labor and delivery preparatory

classes, and neighbor-to-neighbor mentoring programs. The more the sites work with collaborative partners, the better their chances for securing funding and continuing to serve the community.

### *Sustainability takes capitalizing on change, telling the project's story, and building bridges to resources*

The experiences of the 22 Healthy Start sites help provide a framework for sustaining community-based projects. These real examples draw clear pictures of the paths to permanence. These pictures are not road maps, however. The stories have been told; Healthy Start lessons have been taught. Each project must find its own meaning in these words, create its own path, and bring its lessons back to Healthy Start communities and to communities everywhere.



# Appendix

## Sessions Incorporated into Chapter 1

### Medicaid and Managed Care: Its Impact and Implications for Healthy Start

Dr. Peter van Dyck
Medical Advisor, Office of the Director
Maternal and Child Health Bureau
Health Resources and Services Administration
5600 Fishers Lane, Room 18-20
Rockville, MD 20857
Phone: (301) 443-2204
Fax: (301) 443-1797

Susan Tucker
Chief, Maternal and Child Health
Maryland Medicaid Program
201 West Preston Street, Room 135
Baltimore, MD 21201-2399
Phone: (410) 225-6538
Fax: (410) 333-5185

Joan Savoy
Chief of Operations
Great Expectations Healthy Start
1440 Canal Street, Suite 1950A
New Orleans, LA 70112
Phone: (504) 565-7601
Fax: (504) 565-7635

### Leveraging Public Resources

Dr. David Heppel
Director, Division of Maternal, Infant, Child, and Adolescent Health
Maternal and Child Health Bureau
Health Resources and Services Administration
5600 Fishers Lane
Rockville, MD 20857
Phone: (301) 443-2250
Fax: (301) 443-1296

Frank Bonati
President and Chief Executive Officer
Family Health Council, Inc.
625 Stanwix Street
1200 Allegheny Tower
Pittsburgh, PA 15222
Phone: (412) 288-2151
Fax: (412) 288-9036

Chester Pogostin
Public Health Advisor
Centers for Disease Control and Prevention
1600 Clifton Road, N.E.
Mailstop K60
Atlanta, GA 30333
Phone: (404) 488-4410
Fax: (404) 488-4349

Mary Knipmeyer
Associate Administrator
Substance Abuse and Mental Health Services Administration
U.S. Department of Health and Human Services
5600 Fishers Lane, Room 13-99
Rockville, MD 20857
Phone: (301) 443-5184
Fax: (301) 443-8964

Moniquin Huggins
Child Care Program Specialist
Child Care Bureau, Administration for Children and Families
200 Independence Avenue, Rm. 352-G
Washington, DC 20201
Phone: (202) 690-8490
Fax: (202) 690-7441

### Federal Programs Update

Roy Priest
Director of Economic Development
U.S. Department of Housing and Urban Development
431 Seventh Street, S.W., Room 7136
Washington, DC 20410
Phone: (202) 708-2290
Fax: (202) 708-7543

Caroline Lewis
Program Director
HRSA Community Care Corps
5600 Fishers Lane, Room 8-05
Rockville, MD 20857
Phone: (301) 443-6700
Fax: (301) 443-2111

## Sessions Incorporated into Chapter 2

### Challenges in Evaluating Economic Development/ Community Empowerment Initiatives in Healthy Start

Zoe Clayson
Local Evaluation Director
Institute for Health Policy Studies
University of California, San Francisco
1388 Sutter, 11th Floor
San Francisco, CA 94109
Phone: (415) 476-9813
Fax: (415) 476-0705

### Evaluating Diverse Support Services and Activities in Healthy Start

Dorothy Jones Jessup
Director, Research and Evaluation
Medical and Health Research Association of NYC, Inc.
40 Worth Street, Room 720
New York, NY 10013
Phone: (212) 285-0220
Fax: (212) 385-0565

### Evaluating Consortia and Governance within Healthy Start

Dr. Nathalie Vanderpool Bartle
Evaluation Manager
Philadelphia Healthy Start
500 Broad Street
Philadelphia, PA 19146
Phone: (215) 685-6803
Fax: (215) 585-6806

### Evaluating Public Information and Public Education Campaigns

Dr. Patricia O'Campo
Assistant Professor
Department of Maternal and Child Health
Baltimore Healthy Start
The Johns Hopkins University
624 North Broadway
Baltimore, MD 21205
Phone: (410) 955-6836
Fax: (410) 955-2303

## Sessions Incorporated into Chapter 3

### Strategic Planning and Sustainability

Joseph Reid
Office of Grants Development, City of Atlanta
City Hall, Suite 5900
55 Trinity Avenue
Atlanta, GA 30303
Phone: (404) 331-4480
Fax: (404) 331-4515

### Lessons Learned: Community Involvement and Empowerment

Mildred Thompson
Project Director
Oakland Healthy Start
9925 East 14th Street, Suite 11
Oakland, CA 94603
Phone: (510) 639-1246
Fax: (510) 639-0978

Gloria Cox-Crowell
Community Liaison
Oakland Healthy Start
9925 East 14th Street, Suite 11
Oakland, CA 94603
Phone: (510) 639-1246
Fax: (510) 639-0978

Madie Robinson
Project Director
Pee Dee Healthy Start
415 South Coit Street
Florence, SC 29501
Phone: (803) 662-1482
Fax: (803) 662-1039

Michelle Drayton-Martin
Project Director
New York City Healthy Start
99 Hudson Street, 10th Floor
New York, NY 10013
Phone: (212) 334-0250
Fax: (212) 334-6715

Deborah Jack
Co-Chair, Board of Directors
Milwaukee Healthy Women and Infants Project
841 North Broadway, Room 112
Milwaukee, WI 53202
Phone: (414) 286-2466
Fax: (414) 286-5990

## Consumer Caucus

Lillie Fox, Chair
Pee Dee Healthy Start
415 South Coit Street
Florence, SC 29501
Phone: (803) 662-1482
Fax: (803) 662-1039

## Economic Development

Roy Priest
Director of Economic Development
U.S. Department of Housing and Urban Development
431 Seventh Street, S.W., Room 7136
Washington, DC 20410
Phone: (202) 708-2290
Fax: (202) 708-7543

Nolan Lewis
Administration for Children and Families
U.S. Department of Health and Human Services
370 L'Enfant Promenade, S.W., 5th Floor, West Side
Washington, DC 20447
Phone: (202) 401-5282
Fax: (202) 401-5718

Deborah Francis
Project Area Coordinator
Illinois Department of Public Health
100 West Randolph 6-600
Chicago, IL 60601
Phone: (312) 814-4839
Fax: (312) 814-1583

## Resource Availability

Paul Vander Velde
Program Associate
W. K. Kellogg Foundation
One Michigan Avenue, East
Battle Creek, MI 49017
Phone: (616) 969-2235
Fax: (616) 969-2188

Robert Beggan
Senior Vice President
United Way of America
701 North Fairfax Street
Alexandria, VA 22314
Phone: (703) 683-7815

Patricia Pasqual
Director
Foundation Center
1001 Connecticut Avenue, Suite 938
Washington, DC 20036-1401
Phone: (202) 331-1401
Fax: (202) 331-1739

## Leveraging Private Resources

William Randolph
Associate Director, New Initiatives
March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
Phone: (914) 997-4455
Fax: (914) 428-9366

Molly Guard
Director of Program Services
March of Dimes Birth Defects Foundation
5720 LBJ Highway, Suite 180
Dallas, TX 75240
Phone: (214) 458-0110

Patty and Lynne Gartenhaus
Co-Founders and Co-Directors
The Boarder Baby Project
2201 Wisconsin Avenue, N.W.
Suite C-130
Washington, DC 20007
Phone: (202) 333-6500
Fax: (202) 337-9155

### Grantee Communications/ Electronic Linkages

Roland Loudenberg
Director
Data, Information and Reporting
American Association of University
Affiliated Programs
8630 Fenton Street, Suite 410
Silver Spring, MD 20910
Phone: (301) 588-8252
Fax: (301) 588-2842

## Conclusion

### Sustainability

Michelle Lecks
Project Development Manager
Mary's Center
2333 Ontario Road, N.W.
Washington, DC 20009
Phone: (202) 483-8196
Fax: (202) 797-2628

Consumer Voices are drawn from the session *Consumers: Roles, Issues, and Approaches.*

THE INITIATIVE

Maternal and Child Health Bureau

HRSA
Health Resources and
Services Administration

NCE
MCH
National Center for Education
in Maternal and Child Health

BEST COPY AVAILABLE

ISBN 1-57285-024-8